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Áine Sperrin
Doctoral Thesis in Law (PhD, Law)
Submitted to National University of Ireland, Galway
School of Law
March 2018
Dean of the Law School: Dr. Charles O’Mahoney
Supervisor of Research: Dr. Eilionóir Flynn
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Declaration

I certify that this thesis is my own work and that I have not used this work in the course of another degree, either at the National University of Ireland Galway or elsewhere.

Signed: ____________________________
Acknowledgements

I acknowledge with gratitude the financial support from the Irish Research Council from 2013 to 2016, without which I could not have undertaken this research.

My entire PhD experience, from research proposal to final stages has been facilitated by my supervisor, Dr. Eilionóir Flynn. I am extremely grateful for the attention, support, advice and encouragement that Dr. Flynn has given me on my PhD journey and career. It has made my time with the Centre for Disability Law and Policy hugely enjoyable.

On a personal note, the patience and support of Mammy, Daddy and my siblings Tara, Sean John and Paddy Mac throughout my professional and academic endeavours can never be repaid. Special thanks goes to Granny. A lot of wax has been melted through her candle lighting for me over the years and their interventions have always been highly effective and extremely appreciated!

I am extremely grateful to the participants of my qualitative research in Northern Ireland and Bosnia Herzegovina. Thanks also to those who assisted in setting up interviews, translations and preparation of interview materials. The staff and students of the Centre for Disability Law and Policy have influenced my career and aspirations, as well as providing invaluable friendships.

My sanity has remained intact through the countless tea parties with the friends I have encountered in the lovely city of Galway. I know these will be regular occurrences for many years to come. Laura and Charlotte have been especially generous with the Lyons and accommodation and I am very grateful. The encouragement and reassurance from my future house mate has also been very much appreciated.

This thesis is not just the product of an academic programme. Staff and service-users of Cheeverstown House, Dublin first exposed me to the need for ratification of UNCRPD. The Committee members and supporters of the National Platform of Self Advocates further highlighted for me the importance of Article 19 to facilitate full inclusion in society for everyone. Staff at Disability Federation of Ireland and the Irish Human Rights and Equality Commission have also guided the application of my research skills to live disability and human rights issues in Ireland. I hope to be able to effect positive change in the delivery of UNCRPD compliant independent living initiatives for all members of society during my future career both at home and abroad.
Abstract

This research examines the right to live independently and to participate in the community for persons with intellectual disabilities in post-conflict states. This right is provided for under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities. The research focuses on the conflict states of Northern Ireland and Bosnia and Herzegovina.

Independent living is recognized as a fundamental human right in service provision for persons with disabilities. The Independent Living Movement rejected the medical and patriarchal attitude towards persons with disabilities and promoted equality and inclusion. This ethos of inclusion in the community was enshrined in Article 19 of the United Nations Convention on the Rights of Persons with Disabilities.

This research examines international and domestic legislation and policies pertinent to independent living in Northern Ireland and Bosnia Herzegovina. Qualitative research with persons with intellectual disabilities in both jurisdictions was undertaken to address the gaps in knowledge on how persons with intellectual disabilities experienced the periods of conflict, peace process and UNCRPD ratification. Qualitative research with people working in the disability and human rights sectors will ascertain the impact of legislation and policies as well as the legal mechanisms, including litigation, which individuals and representative groups can utilize to realize their rights.

This research identifies lessons to be learned by the international community in the creation of a society inclusive of persons with intellectual disabilities in the wake of conflict, with a particular focus on the right to live independently.

List of Abbreviations
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<tr>
<th>Acronym</th>
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<tr>
<td>AJuPID</td>
<td>Access to Justice for Persons with Intellectual Disabilities</td>
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<td>BCODP</td>
<td>British Council of Disabled People</td>
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<tr>
<td>BiH</td>
<td>Bosnia Herzegovina</td>
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<tr>
<td>BIHLE</td>
<td>Bosnia Herzegovina Lived Experience</td>
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<td>BIHP</td>
<td>Bosnia Herzegovina Professional</td>
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<td>CIL</td>
<td>Centre for Independent Living</td>
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<td>CSO</td>
<td>Civil Society Organisation</td>
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<tr>
<td>DHSPSS</td>
<td>Department of Health, Personal and Social Services</td>
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<td>DPO</td>
<td>Disabled Person’s Organisations</td>
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<td>EU</td>
<td>European Union</td>
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<td>FBiH</td>
<td>Federation of Bosnia Herzegovina</td>
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<td>ILM</td>
<td>Independent Living Movement</td>
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<tr>
<td>ICCPR</td>
<td>International Covenant on Civil and Political Rights</td>
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<td>ICESCR</td>
<td>International Covenant on Economic, Social and Cultural Rights</td>
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<td>NHRI</td>
<td>National Human Rights Institution</td>
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<td>NI</td>
<td>Northern Ireland</td>
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<td>NILE</td>
<td>Northern Ireland Lived Experience</td>
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<td>NIP</td>
<td>Northern Ireland Professional</td>
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<td>NGO</td>
<td>Non-Governmental Organisations</td>
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<tr>
<td>OFM/DFM</td>
<td>Office of the First Minister/Deputy First Minister (Northern Ireland)</td>
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<tr>
<td>OHCHR</td>
<td>Office of the High Commissioner for Human Rights</td>
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<td>UDHR</td>
<td>Universal Declaration of Human Rights</td>
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<td>UN</td>
<td>United Nations</td>
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<td>Abbreviation</td>
<td>Full Name</td>
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<td>UNCEDAW</td>
<td>United Nations Convention on the Elimination of All Forms of Discrimination Against Women</td>
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<td>UNCRC</td>
<td>United Nations Convention on the Rights of the Child</td>
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<tr>
<td>UNCRPD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<tr>
<td>UK</td>
<td>United Kingdom</td>
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<td>US</td>
<td>United States</td>
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List of Instruments

International

Declaration on the Rights of the Mentally Retarded (1971),

Declaration on the Rights of Disabled Persons (1975)

World Programme of Action concerning Disabled Persons (1982)


Tallin Guidelines for Action on Human Resources Development in the Field of Disability (1990)

Principles for the Protection of persons with Mental Illness and the Improvement of Mental Health Care (1991)


European Union Charter on Fundamental Rights (2000)


Millennium Development Goals (2000)

United Nations

Universal Declaration of Human Rights Article

United Nations Convention on the Rights of the Child

United Nations Committee Against Torture Cruel, Inhuman and Degrading Treatment

United Nations Committee on the Rights of the Child

Standard Rules on the Equalization of Opportunities for Persons with Disabilities


Convention on the Rights of the Child

General Comment No. 5 of the Committee on Economic, Social and Cultural Rights
United Nations Convention Against Torture, Cruel, Inhuman and Degrading Treatment

Standard Rules on the Equalization of Opportunities for Persons with Disabilities

**United States**

Civil Rights Act 1964
Rehabilitation Act 1973
Americans with Disabilities Act 1990.

**Great Britain and Northern Ireland**

1914 Special Constables Act
Chronically Sick and Disabled Persons (Northern Ireland) Act 1972
Mental Health (Northern Ireland) Order 1986, Part IV.
Education and Libraries (NI) Order 1986
Disability Grants Act 1993
Disability Discrimination Act 1995
Good Friday Agreement 1998
Disability Discrimination (Northern Ireland) Order 2006
Disabled Persons Employment (Northern Ireland) Act 1944
Trading Representations (Disabled Persons) Act 1958
Housing Act (Northern Ireland) 1963
Chronically Sick and Disabled Persons Act 1970
Housing Executive Act (NI) 1971
Health and Personal Social Services (Northern Ireland) Order 1972
Northern Ireland Act 1974
Chronically Sick and Disabled Persons Act 1976
Chronically Sick and Disabled Persons Act 1978
Rating (Disabled Persons) Act 1978

Disabled Persons Act 1981

Mental Health (Northern Ireland) Order 1986

Disabled Persons (Services, Consultation and Representation) Act, 1986

Education and Libraries (NI) Order 1986

Disabled Persons (Northern Ireland) Act 1989

Disability Living Allowance and Disability Work Allowance Act 1991

The Disability Living Allowance and Disability Working Allowance (Northern Ireland) Order 1991

Disability Grants Act 1993

Joint Declaration on Peace: The Downing Street Declaration, Wednesday 15 December 1993

Civil Rights (Disabled Persons) Bill1994

Disability Discrimination Act 1995

Northern Ireland Act 1998 and the Departments (Northern Ireland) Order 1999

Human Rights Act 1998

Carers and Direct Payments (Northern Ireland) Act 2002

Health and Social Care (Reform) Act (Northern Ireland) 2009

Bosnia Herzegovina

Constitution of Yugoslavia (1963)


Law on Federal Ministries and other bodies of the Federal Administration („Official Gazette of the Federation BiH” No. 8/95, 3/96, 9/96 and 48/99

Republica Srpska Law on Social Welfare 1996
Law on Receivables in the Privatization Process Based on Difference in Income of the Beneficiaries Exercising the Pension and Disability Insurance Rights\(^1\) (1998 and 2002),

1998 Law on Modifications and Amendments to the Law on Pension and Disability Insurance of the Federation of Bosnia and Herzegovina

Law on Organisation of the Pension-Disability Insurance Fund in the Federation of Bosnia and Herzegovina\(^1\) (1999),

Law on Core Issues of Social Care, Care for the War-Disabled Civilians and Care for the Families with Children.

Law of 1999 on Principles of Social Protection, Protection of Victims of War, and Protection of Families with Children [Bosnia and Herzegovina], 6 September 1999,

1999 Law on Core Issues of Social Care, Care for the War-Disabled Civilians and Care for the Families with Children

Law on Protection of Persons with Mental Disorders in 2001

FBiH 2002 Law on Administrative Procedure from 2002 Official Gazette’ of Bosnia and Herzegovina, No. 29/02, 12/04

Law on the Protection of Persons with Mental Disorders in the Republica Srpska, Official Gazette of the Republic of Srpska’, No. 46/04

Official Gazette of Brčko District of BiH’, No. 2/10.

Law Date File on Insurees and Beneficiaries of the Pension and Disability Insurance Rights (2011)

Law on Master Record on insured persons, persons obliged to pay contributions and beneficiaries of the pension and disability rights (2011)

Law on Professional Rehabilitation and Employment of Persons with Disabilities FBiH

Republica Srpska the Law on Social Protection 2015
Chapter One: Introduction and Methodology
1.1 Introduction
Chapter One will introduce the contents of this thesis, describe how I came to undertake this research and explore the central research questions. It will then explain the rationale behind the terminology used throughout the thesis and the methodology employed in designing, conducting and analysing the data obtained through desk based research and qualitative interviews.

Chapter Two provides an overview of the Independent Living Movement. The ethos of the Independent Living Movement was the precursor to the human right which is the focus of this research, namely Article 19 of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). It then discusses the academic and grey literature pertaining to the right to independent living contained in other human rights instruments, the process of drafting the UNCRPD and more specifically Article 19 of this Convention. It will examine international guidance from the United Nations and regional human rights organisations on the implementation of Article 19. This will establish the standards against which the selected jurisdictions of Northern Ireland and Bosnia Herzegovina are being examined.

Chapter Three focuses on the legislation and policies pertaining to independent living for persons with intellectual disabilities in Northern Ireland. It examines the period from the starting point of the Troubles in the late 1960s through to the peace process during the 1990s and to the present day. The research combines literature with contributions from participants in qualitative research to ascertain the reality of the lives of persons with intellectual disabilities during this timeframe.

Chapter Four focuses on the legislation and policies pertaining to independent living in Bosnia Herzegovina. It examines the period from the starting point of ethnic tensions during the 1980s, through the period of conflict from 1992 to 1995, the peace process and to present day. It will combine contributions from participants of qualitative research regarding their personal and professional experiences of the impact of the conflict and peace process on the rights of persons with intellectual disabilities to live independently today.

Chapter Five compares the jurisdictions in light of themes identified through combining the literature available and information obtained through interviews. It discusses the impact of the conflict on legislation and policies related to independent living. It offers recommendations on how states can best realise the right of persons with disabilities to live independently and be included in the community when emerging from a period of ethno-
nationalist conflict. These recommendations are based on the values and principles enshrined in the UNCRPD. While they are tailored to the context of this research the recommendations are conducive to promoting Article 19 compliance in states which have not experienced conflict but any disruption to the political, economic, social or cultural status quo.

1.2 Research Questions
The primary aim of this research is to assess the impact of domestic national conflict on the experiences of adults with intellectual disabilities realizing the right to live independently in society. It will combine analysis of legislation and policies pertaining to independent living for persons with intellectual disabilities and thematic analysis of qualitative research conducted in the field. The qualitative research involved interviews with two groups of people - five persons with intellectual disabilities and five persons from the disability service and human rights sectors in each jurisdiction. The participants with lived experience of disability were aged over 40 as they had to be adults when the conflict started. The post-conflict states of BiH and NI were selected as the focus of the research. These states lend themselves to comparative research as both conflicts were ethno-nationalist in nature, the peak of the conflicts and peace processes occurred during the 1990s and both have decentralised governance structures within states which have ratified UNCRPD. However, the nature (genocide/sieges/combat versus paramilitary activity/isolated bursts) and duration (three years versus thirty years) of the conflicts do differ as well as the economic prosperity of the states. Conducting comparative research of these states can contribute to extrapolating conclusions which can potentially resonate with present and potential future challenges in NI and BiH and states experiencing similar civil ethno-nationalist conflict. While the primary research question is outlined above, in order to ascertain the impact of domestic national conflict on the right to live independently for adults with intellectual disabilities narrower questions had to be addressed. These connected questions will allow the research to outline

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1 This research does not attempt to address issues surrounding the causes of conflict and does not reflect the wide literature on conflict, ethno-nationalist conflict or transitional justice. The research accepts ethno-nationalist conflict occurred in both NI and BiH in accordance with the discussion by Wimmer, Cederman and Min. 'Ethnic Politics and Armed Conflict: A Configurational Analysis of a New Global Data Set', American Sociological Review, 2009, Vol. 74, April, 316-337.

the national provisions pertaining to organizing disability services and supports considering
the political and social contexts of the periods. These are discussed below.

1. How were the lives of persons with intellectual disabilities impacted by legislative
and policy measures governing disability services supporting independent living in
years immediately preceding the conflicts?

Legislation and policies as well as academic and grey literature will be examined to ascertain
the nature and extent of State provided disability services. Contributions from professionals
and persons with lived experience will offer insight into how persons with intellectual
disabilities lives were impacted by legislation and policies. While there is a significant
amount of policy documents and legislation available on disability services in Northern
Ireland for these time periods, similar information is significantly lacking in Bosnia
Herzegovina. The most authoritative report in Northern Ireland which provides information
on disability services in the recent past is the Bamford Review. This document
acknowledges the gap in this knowledge about the lived experience of persons with
intellectual disabilities and suggests that the experience of conflict would be similar to that of
the non-disabled population. No research purports to reflect the experiences of persons with
intellectual disabilities in BiH and only general assumptions incorporating the communist
nature of states in the region are available. These questions will be answered through a
combination of desk based and qualitative research with both groups of interview participants
in Chapter 3 (Northern Ireland) and Chapter 4 (Bosnia Herzegovina).

2. How were intellectual disability services impacted by the conflict and what were the
experiences of persons with intellectual disabilities during the conflict in these states?

This question aims to ascertain the extent of disruption inflicted by conflict on disability
services. It also seeks to explore the extent to which persons with intellectual disabilities
engaged with and experienced the conflict. This question will be answered almost exclusively
through qualitative research with both participant groups in the two jurisdictions. This can
serve to provide guidance for humanitarian organisations during, or in the aftermath of,
conflict or similar disruption as well as the factors to be considered from the outset of peace

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3 Bamford Review Steering Committee, ‘The Bamford Review of Mental Health and Learning Disability
and re-building. This question will be addressed in Chapter 3 (Northern Ireland), Chapter 4 (Bosnia Herzegovina) and Chapter 5 (Discussion and Conclusions).

3. To what extent were the rights of persons with intellectual disabilities to live independently considered in post-conflict societies during state re-building?

This question seeks to examine how, if at all, the rights and needs of persons with disabilities are considered by states tasked with rebuilding fundamental democratic, legal, social and cultural structures. Typically conflict originates from, or results in, the deprivation of fundamental civil, political, social, economic or cultural rights of a targeted group who have experienced marginalization in their societies. Therefore, this research will seek to ascertain whether the rights of persons with intellectual disabilities is improved in unison with the enjoyment of rights by the general population and in the context of increasing stability of the state. This question will be answered through the analysis of the combination of qualitative and desk based research in Chapter 5 (Discussion and Conclusions).

4. To what extent have Northern Ireland and Bosnia Herzegovina complied with their obligations under Article 19 UNCRPD - to facilitate independent living and inclusion in the community for persons with intellectual disabilities?

This question seeks to extrapolate learning from the experiences of the two jurisdictions with due consideration of the conflict situations to inform future legislation and policies surrounding independent living which can be applied to other states. Both jurisdictions have been examined by the Committee on the Rights of Persons with Disabilities but this question considers the role of the conflict in the promulgation of the legislation, policies and practices adjudicated upon by the Committee. This question will be answered through the analysis of the qualitative and desk based research discussed at Chapter 5 (Discussion and Conclusions).

The conflict in these jurisdictions is widely researched across numerous disciplines but the focus on intellectual disability is markedly absent. Brigitte Rohwerder\(^4\) has asserted that intellectual disability within conflict is a neglected area of research\(^5\). Fabricio Balcazar, has

\(^{4}\) Research Officer, Conflict and Violence Cluster, Institute of Development Studies, University of Sussex, Brighton.

\(^{5}\) Email communication with Dr. Brigitte Rohwerder on 28 September 2016, on file with researcher.
similarly indicated a dearth in available data on persons with intellectual disabilities in Bosnia Herzegovina. Wave Trauma Centre have highlighted the lack of disability related conflict research in Northern Ireland and the Bamford Review also indicated that there is no information available on the experiences of persons with intellectual disabilities of the Northern Ireland conflict. Further, an interviewee in Northern Ireland indicated that this is a niche area of research and was surprised when I suggested that much more literature was available in NI than BiH: ‘I can only imagine how bad that is then’. The interviewee further stated ‘[t]here’s been so little research gone into the effects of the Troubles [on persons with intellectual disabilities]’. These perceptions among leading academics and practitioners are indicative of the novel contribution of this research to the field of disability law and policy.

Throughout this research the situation of conflict acts as a backdrop to the analysis on legislation and policies pursuing independent living in practice. This research does not aim to analyse the causes of conflict, the events and violence perpetrated during conflict or the success of the peace processes outside of their impact on independent living. Analysis of the post conflict situation was undertaken to determine the capability of countries experiencing complex political, economic and social climates to adhere to Article 19 UNCRPD at a time when states without such limitations fail to even ratify UNCRPD. This research aims to highlight the steps taken by NI and BiH in fulfilling the provisions contained within Article 19 UNCRPD. Ultimately the research aims to influence future policy for independent living for countries newly engaging with UNCRPD and which may be emerging from conflict or disruption to the political, social, economic and cultural climate.

1.3 Terminology and Concepts

The terminology used throughout this research has been adopted from the UNCRPD. The term ‘persons with disabilities’ encompasses an undefined range of people who experience barriers to participation in society on an equal basis with others. This can include physical, intellectual, mental, psycho-social or sensory impairments. I acknowledge the social

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6 Email communications by researcher with Dr. Balcazar on 2 June 2016, on file with researcher.
8 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
9 Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
10 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
12 Ibid.
model’s differentiation of ‘disabled person’ as reflecting the obstacles created by society which results in exclusion and the physical or intellectual impairment experienced by the individual. However, I have selected the human rights model of disability for the purposes of this research which builds on the social model of disability which Degener suggests can improve the understanding and implementation of the UNCRPD. As such, I do not use the term ‘impairments’, instead using the term ‘persons with disabilities’, ‘persons with physical disabilities’ and ‘persons with intellectual disabilities’ to describe the target group of this research. While this does not replicate Article 1 of UNCRPD, it does reflect the text of Article 19 UNCRPD which is the focus of this research and the most recent terminology used by the UNCRPD Committee in the issuance of Concluding Observations to States and General Comments.

1.4 Human Rights Model of disability

The social model of disability emerged from the Independent Living Movement and has been discussed throughout this literature review. Degener suggests that the UNCRPD lends itself to an alternative model which better serves the rights of persons with disabilities\textsuperscript{13}. The human rights model of disability has been developed based on Degener’s experience of the Committee on the Rights of Persons with Disabilities. Having foundations in the practical implementation of UNCRPD the human rights model lends itself effectively as a framework for this research which seeks to ascertain the impact of Article 19 UNCRPD on the lives of persons with intellectual disabilities. The human rights model rejects the medical and individualised focus which existed before the Independent Living Movement and goes further than the social model to place the inherent dignity and value of the individual at the centre of being a rights holder\textsuperscript{14}. The combination of civil, political and economic, social and cultural rights also lends itself to the achievement of UNCRPD ideals which require both non-discrimination and positive social, economic and cultural facilities\textsuperscript{15}. The human rights model recognises difference of experience through disabilities including pain and physical and intellectual restrictions\textsuperscript{16}. It also provides scope for reflecting individual diversity outside of disability – ethnicity, sexuality and gender for example\textsuperscript{17}. In this way it recognises persons

\textsuperscript{14} Ibid at p. 5.
\textsuperscript{15} Ibid at p. 8.
\textsuperscript{16} Ibid at p. 12.
\textsuperscript{17} Ibid at p. 17.
with disabilities as having intersectional experiences in the same way as persons without disabilities. The model can be utilised to incorporate disability rights into the broader human rights framework against which public policies are screened for compatibility. This can be useful for National Human Rights Institutions whose mandate includes the promotion of human rights and equality at policy making level. In an international context Degener argues that the human rights model can also be incorporated into development policies for social justice. The human rights model is also particularly suited to the research of Northern Ireland’s disability landscape as it has encouraged for use at a national level in the UK during their examination by the Committee on the Rights of Persons with Disabilities.

Considering the research questions identified for this thesis, the determination of the effectiveness of independent living initiatives in NI and BiH, the human right model fully recognises persons with intellectual disabilities as rights holders, their diversity as individuals with ethnic identities and facilitates consideration of UNCRPD compliance in situations of international development, typically associated with post-conflict situations. The human rights model is an effective prism through which to evaluate the compliance of NI and BiH with their Article 19 obligations and to generate recommendations for future actions by these and other post conflict states.

While the UNCRPD does not define disability, in order to focus my research and to recruit participants I did have to consider what is meant in this research by the term ‘intellectual disability’. I have adopted the description utilized by the European project Access to Justice for Persons with Intellectual Disabilities (AJuPID). Individuals who have the label of an intellectual disability can and should be described in many other ways including, friend, neighbour, relative, parent, colleague, community member, employee, employer and parent. They may have difficulty with certain cognitive skills, although this varies greatly among individuals. We adopt a progressive understanding that ability-disability is a continuum that all human beings exist on at various stages in our lives, where disability is an infinitely

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18 Ibid at p. 23.
19 Section 42 of The Irish Human Rights and Equality Commission Act 2014 provides for a Public Sector Duty mechanism whereby the NHRI can promote and liaise with public bodies to screen policies and activities for human rights and equality impact. Similarly Section 75 of the Good Friday Agreement allows for a similar duty on public bodies which will be discussed in Chapter 3.
21 Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland, 3 October 2017 at para 6(b).
various but universal feature of the human condition’. This definition reflects the ambition of this research, to gain knowledge on the independent living experiences of individuals with intellectual disabilities before, during and after a period of conflict. These experiences will naturally include family, friends and colleagues etc., and there has been a continuum of cognitive skills reflected in the cohort of participants.

In NI the term ‘learning disability’ is prevalent and is referred to in documents and during interviews. In BiH the terms ‘persons with disabilities’ and ‘persons with intellectual disabilities’ was relayed to me by participants and interpreters during the fieldwork. Persons referred to by the terms ‘learning disability’ and ‘persons with intellectual disabilities’ adhere to the description adopted from AJuPID. Throughout this thesis, older rhetoric that is currently considered offensive will be directly quoted in its historical contexts and the use of these terms is not an endorsement of these terms in the current context. Where these terms appear in the literature or legislation I quote directly from these sources. This approach contributes to demonstrating the changing use of language in relation to persons with disabilities in line with increased respect for rights.

Chapter 2, Literature Review, will discuss institutionalisation and de-institutionalisation in more detail but it is useful to highlight these terms here. This research adheres to the definition of an institution by the European Coalition for Community Living: ‘An institution is any place in which people who have been labelled as having a disability are isolated, segregated and/or compelled to live together. An institution is also any place in which people do not have, or are not allowed to exercise control over their lives and their day-to-day decisions. An institution is not defined merely by its size.’ Connected to this then, deinstitutionalisation is the process in which persons with disabilities exercise choice and control over their own lives, activities, and their place of residence and with whom they live. They have access to services in the community on an equal basis with others and avail of all necessary supports to enable them to live their lives.


The ‘Troubles’ is most frequently used in NI to describe the conflict, where ‘the war’ or ‘conflict’ was used to describe the same in BiH. Both of these terms are socially and politically neutral. The terms were used at the time of conflict and continue to be used today. The terms do not denote affiliation with any party to the conflict.

1.5 Methodological approach

The over-arching method of this thesis is comparative socio-legal research. To address the considerable gaps in the information required to answer the research questions I conducted qualitative interviews with persons with lived and professional experiences of the topic. I considered disability studies theory in designing and conducting the qualitative research and then employed thematic analysis of the data generated.

As is evident from the research questions, the research seeks to assess the impact of conflict on the realisation of Article 19 UNCRPD on legislation, policies and the lives of persons with intellectual disabilities in NI and BiH. It was necessary to undertake qualitative research to get a sense of the lived experience of persons with intellectual disabilities in these jurisdictions. The qualitative research does not presume to provide a comprehensive overview of the experiences of persons with intellectual disabilities in both jurisdictions during these periods. Rather, this research merely provides an illustrative account of the participants’ personal and professional experiences.

A human rights model of disability will be utilised to assess the compliance of NI and BiH with their obligations under UNCRPD. This will be discussed further in the Literature Review.

1.5.1 Comparative socio-legal research methods

Comparative socio-legal analysis was undertaken of international and domestic legislation and policies, to determine the type and range of disability services in two post-conflict jurisdictions. This analysis encompasses the periods in NI and BiH immediately preceding and during the conflict and after the peace agreements each country has implemented. The research design has been drawn from McDougal’s approach to comparative legal research. McDougal highlights the need for comparative legal research arising from the collective interest in common values being emphasized internationally. The concepts typically

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25 This is further discussed at Chapter 2, Section 2.11.
subjected to comparative legal research in his view include the sharing of power, access to resources, respect, dignity and the equal opportunity to express individual values.\(^{27}\)

The universal values typically pursued by comparative socio-legal researchers espoused by McDougal include equality. In this research the common values are those contained within UNCRPD and specifically Article 19\(^{28}\). The alignment of these values with the ethos of the Independent Living Movement and the relative novelty of the operation of the UNCRPD reinforces the suitability of this research to comparative socio-legal methods. The sources for the research are also closely aligned with those described by McDougal as essential for the achievement of common values. These sources for the achievement of common values are the bases of power, which encompasses both the formal authority and limitations (through constitutional provisions) on government, effective controls, such as political parties and pressure groups. The sources also include practices of how the formal authorities and effective controls exert their powers and influences. The final source is the effect that the distribution and acting on powers and control by the formal authorities and effective controls have on the target group. In NI and BiH the formal authorities are the national governments while the effective controls are the political parties representing ethnic groups and disability representative and human rights organisations. The practices of exerting power is through the devolved administrations and the provision of disability services. The effect then is garnered through the qualitative research with persons with lived experience and professionals in the relevant sectors. This has been borne out in the interviews with professionals in both jurisdictions who indicated the active role comparing issues with neighbouring jurisdictions has in their work.\(^{29}\)

McDougal highlights the potential for influence by the action of one state on the domestic behaviour of others\(^{30}\). He claims that effective comparative legal research must assess the impact of legislation over time\(^{31}\) and consider the ‘whole community context’\(^{32}\). As well as legislation and policies, comparative socio-legal research must have due regard for community values such as class and attitudes. McDougal asserts that comparative socio-legal

\(^{27}\) Ibid pp 916-917.
\(^{28}\) The provision contained with Article 19 of the United Nations Convention on the Rights of Persons with Disabilities will be discussed in Chapter 2, Section 2.9.
\(^{29}\) Participants from the professional group who are involved with statutory agencies emphasized the impact of progress or regression in neighbouring states as influential on their roles in both jurisdictions.
\(^{31}\) Ibid at p. 919.
\(^{32}\) Ibid at p. 922.
research must recognize that decisions are made at levels other than nation states. This is particularly relevant to this research as both NI and BiH contain devolved governance structures. While there is accountability at a national level for adherence to UNCRPD, the duty to implement independent living programmes is generally conducted at a local administrative level. McDougal continues to suggest a method of analysis for comparative socio-legal research. This involves analysis of the global and national power processes as well as what is described as the value processes; how issues affecting the community are organized. This relates to this research as I am examining the extent of compliance with an international standard, Article 19 UNCRPD in NI and BiH. Finally he suggests analysis of how private associations might influence power. This is relevant to my research as non-governmental organisations, charities and disability service providers are involved in the provision of independent living supports for persons with intellectual disabilities. These are extremely informative and valuable categorisations that were incorporated into the design of the qualitative research questions.

The legislation and policies examined in this research span five decades thus adhering to the need to consider the impact of law and policy through time as McDougal suggests. The criticism that comparative legal research is removed from community values and fails to adapt new means to address discrepancies\textsuperscript{33} is also mitigated in this research in two ways. Firstly I have engaged in fieldwork, meeting with persons affected by the issue being researched and visiting the places where the issues occurred\textsuperscript{34}. Secondly, I have employed methods to ensure accessibility of material relevant to the research topic to adults with varying communication needs, and intend to do so for research findings also\textsuperscript{35}. In this instance the research questions are organized around ascertaining how persons with disabilities are affected by the ‘whole community context’.

The devolved and complicated nature of the governance structures of NI and BiH are prime examples of decision-making power lying other than with the State itself. This is especially relevant when issues surrounding ethnic minorities and conflict are being considered. While it has not been feasible for my research to examine provisions relating to disability in each

\textsuperscript{33} \textit{Ibid} at p.920.
\textsuperscript{34} Immersion in the field will be discussed at Section 1.5.4.
\textsuperscript{35} I have been invited back to a Northern Ireland based advocacy group to present my research findings and will develop accessible information material for this presentation and distribution to other advocacy organisations.
individual canton in BiH, the qualitative research offers insight\textsuperscript{36} which is reflective of the wider experience. Further, the consideration of Northern Irish provisions delve into the ‘formal authority and effective control’ which Mc Dougal urges to be examined\textsuperscript{37}, as exercised over persons with intellectual disabilities within the United Kingdom. Not all disability legislation from the UK applied equally to Northern Ireland so policy provided more guidance for providers of health and social services in this respect and was examined during this research accordingly. The complex governance system in Bosnia Herzegovina has resulted in fragmented disability and social service legislation and policies as each canton devises their own. It is this element of the research which can be novel and complimentary to the investigations by the monitoring bodies of international human rights treaties which are empowered to consider the State in its entirety.

Human rights provides the foundation for the framework of the assessment of data gathered through this thesis. The United Nations system of engaging states to agree on international human rights instruments and the monitoring thereof is central to the research. I supplemented my existing knowledge from earlier studies and career to understand how these mechanisms operate with a disability specific focus. I first conducted an in-depth literature review on the Independent Living Movement, UNCRPD and Article 19 to gain an insight into the origins of what is currently understood as independent living for persons with intellectual disabilities. The fundamentals of equality, dignity and respect prevalent throughout all UN human rights treaties resonates with the Independent Living Movement and so the UNCRPD was determined to be an appropriate framework through which to examine my research questions. Once I had established the norms and standards for independent living I investigated the legislative and policy provisions pertaining to services for persons with disabilities and intellectual disabilities. I considered the evolution of these services towards independent living, or lack thereof, in each jurisdiction. I also conducted research on the timeline and main events of the conflicts from historical and conflict studies research journals but this was not to the fore of focus of the desk based research.

\textsuperscript{36} BIHP5 indicated that accounts from other cantons would involve very similar details as to lived experience and the difference would be the ethnic perspective of the conflict. BIHP5: \textit{It would be the same things, using different words but it would be the same issue.}\ Extract from interview with BIHP5, 7 August, 2016, transcript on file with researcher. My research has reinforced this assertion that experiences of the participants during the conflict were the same regardless of ethnicity. This is further discussed in Chapter 5.

1.5.2 Qualitative research in the field of Disability Studies

1.5.2 Researcher Positionality

This PhD was initially motivated by my voluntary experiences with a disability service organisation in Dublin in 2010. In this role I engaged with service-users and staff and conducted research. This research contributed to the disability service’s internal monitoring mechanism – the Rights Review Committee. The Rights Review Committee considers the impact of organisational policies and staff activities on the fundamental rights of service-users. The process of de-institutionalisation was a priority issue in this residential service for adults with intellectual disabilities. This is a policy pursued by the Health Service Executive to cease the practice of segregated residential institutions for adults with disabilities from their communities in Ireland. I conducted rudimentary research on the human rights implications of issues which arose for the Rights Review Committee.

I attended the inaugural United Nations World Down Syndrome Day 2012 at United Nations headquarters in New York, where I was based at the time, and was exposed to an international perspective on the UNCRPD. The speakers discussed challenges surrounding living independently internationally. This prompted me to question how lesser resourced states, including those which have experienced conflict, can hold themselves accountable to the standards of the UNCRPD while Ireland delayed ratification. The scope of the research topic was further narrowed after consultation with Dr. Eilionóir Flynn at the Centre for Disability Law and Policy. Over the next year, during which time I interned at Irish and UK human rights organisations, a proposal was developed and I successfully obtained Irish

38 Rights Review Committees were established in recognition of the potential for rights abuses through standard operating procedures in disability services. It is currently considered essential to facilitate a Rights Review Committee to comply with best practices. Federation of Voluntary Bodies Ireland, ‘Rights Review Committees Functions and Challenges’, <<http://www.fedvol.ie/_fileupload/Sharing%20Innovative%20Learning/Doing%20Things%20in%20the%20Right%20Way/Right%20Review%20Committee%20overview%20SHS%20Updated%20Maura%20Loughlin.pdf>> accessed 4 October 2017.


41 My experience at Oxfam Ireland exposed me to the work of international aid organisations for whom disability issues should be embedded in their modus operandi. My experience with the Irish Human Rights Commission (legacy body to the Irish Human Rights and Equality Commission) exposed me to the work of a National Human Rights Institution and my work with Rights Watch UK focused on highlighting the on-going human rights implications of the repercussions of actions by the British government during the Troubles in Northern Ireland.
Research Council funding, to commence my PhD in September 2013. The initial proposal was to conduct a comparative analysis of how the post conflict experiences in Northern Ireland and Bosnia-Herzegovina impacted their potential to provide independent living to adults with intellectual disabilities. Deepening my understanding of disability theory and the drafting process of the UNCRPD and the principles contained therein was a key task before turning to the comparative research.

Disability studies have provided the academic sector with important arguments towards the inclusion of persons with disabilities, including intellectual disabilities in qualitative research. I will discuss these now.

I am cognizant that I am conducting this research as a researcher without lived experience of disability. I am aware that I have decided the topic and scope of the research within an academic setting. In conducting qualitative research I am seeking particular information to address gaps in literature to address the research questions identified at the outset. I have attempted to mitigate Barnes’ arguments and concerns against the ‘independent researcher’ as far as practicable. These relate to the exclusion of persons with disabilities as researchers due to the traditional academic foundations of disability research. Barnes is further critical of the link to funding in academic endeavours without consideration for persons with disabilities as the target audience of disability research. Further the link to funding and short term research contracts on disability issues which have been medical focused and limit the potential for new ideas being investigated is criticised by Barnes. In the absence of access to disabled persons organisations’ run and controlled by persons with intellectual disabilities in the jurisdictions being studied, I sought assistance from organisations representing the rights of persons with intellectual disabilities at national levels. I ensured these organisations had branches which were locally based to ensure they were best placed in their communities to

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44 Ibid
identify participants. Shakespeare\textsuperscript{45} has defended research of disability issues by non-disabled academics and I incorporated his methods of conducting qualitative research with persons with disabilities – fully explaining the research (through Easy to Read participant information sheets and consent forms\textsuperscript{46}) and encouraging participants to ask questions about myself and the research.

Goodley’s\textsuperscript{47} conception of disability studies research as a continuum was also a contributing factor in the design of my research and consideration of how to combine qualitative research and desk-based research. Goodley outlines three stages along the disability research continuum: (1) non-participatory which is completely research led, (2) participatory which entails some involvement by persons with disabilities in the research and (3) emancipatory which entails the researcher and persons with disabilities as equal partners in the research. As the research proposal has been developed by the researcher (with support from a non-disabled supervisor) and is being conducted as part of a PhD programme at an academic institution it would be considered non-participatory due to the academic analysis of available and self-generated material. However, I would argue that my research is informed by participatory and emancipatory research due to the prioritization of disabled persons’ experiences to validate or challenge existing rhetoric. My role as a support person to the National Platform of Self Advocates in Ireland\textsuperscript{48} has made me more aware of the importance of the voice of the lived experience and I have endeavoured to incorporate this into my personal approach to the research.

My research involved the establishment of professional relationships with disability and human rights organisations who have expressed interest in receiving the findings and conclusion of the research for use by their advocates and staff. In this way the research will not be confined to the academic sector. I will produce a summary of my research findings,


\textsuperscript{46} Guidance was utilised from Inclusion Europe ‘Information for All. European standards for making information easy to read and understand’, <<<http://www.inclusionireland.ie/sites/default/files/attach/book-page/1436/european-easy-read-standards.pdf>>> accessed 20 November 2015. Also an online UK based service was used. This provides a gallery of images suitable for use in Easy to Read formats – ‘Easy on the III’, <<<http://www.easyonthei.nhs.uk/> accessed 18 November 2015.


\textsuperscript{48} The National Platform of Self Advocates are an organisation representing adults with intellectual disabilities in the Republic of Ireland. <<<http://thenationalplatform.ie> accessed 5 November 2017. I was involved as a support person through the Centre of Disability Law and Policy from October 2013.
including in Easy to Read format\textsuperscript{49}, and make these available to disability and human rights organisations in Northern Ireland, Bosnia Herzegovina and Ireland.

\textbf{1.5.3 Qualitative research methods}

The aim of the qualitative research of this project has always been to ensure that the experiences of people whose lives are affected on a daily basis – personally and professionally – are included to verify or challenge the rhetoric of State documentation and legislation. Persons with intellectual disabilities were included in the research to provide personal accounts of their interaction with families, support services, education, employment and the conflict and peace process. Professionals in the areas of law, policy, disability rights advocacy and disability services were interviewed to ensure I had included the most relevant legislation and policies in my literature review and also to offer insight into how these were administered by state and non-state agencies. Quinn and Degener\textsuperscript{50} have highlighted the importance of the role of disability advocacy organisations\textsuperscript{51} and policy-makers\textsuperscript{52}, including National Human Rights Institutions\textsuperscript{53} in the recognition of disability rights as equal to all human rights. These stakeholders can contribute to the implementation of effective policies and the realization of the rights of persons with intellectual disabilities. The inclusion of staff from disability services in ascertaining the prevalence of abuse and monitoring standards is also widely utilized by disability researchers. Owen and Griffiths\textsuperscript{54} highlight the role of disability service providers in the most intimate elements of service-users’ lives while Dempsey and Nankervis’\textsuperscript{55} examination of organisational elements of community disability services further reinforced for me the need to include these perspectives in my research.

While the interviews did use a set of questions to guide the conversation, and attempt to address the gaps in the literature, it was largely anticipated that the conversations between the questions would lead to themes emerging that literature has not been able to capture to date.

\textsuperscript{49}I will repeat the method used to produce the qualitative research materials and ensure feedback from a self-advocate with an intellectual disability is incorporated.


\textsuperscript{51}Ibid at Chapter 10.

\textsuperscript{52}Ibid at Chapter 10.

\textsuperscript{53}Ibid at Chapter 11.

\textsuperscript{54}Owen, F., and Griffiths, D., ‘Challenges to the Human Rights of Persons with Intellectual Disabilities’, Jessica Kingsley Publishers (2008.), 199. The authors discuss the potential barrier that service providers can perpetuate in relation to the realization of sexuality for persons with intellectual disabilities.

\textsuperscript{55}Dempsey, I. J., and Nankervis, K., ‘Community Disability Services: An Evidence Based Approach to Practice’ Purdue University Press (2006), Part 3 ‘Working in Disability Services’.
Cohen and Crabtree\textsuperscript{56} outline the usefulness of semi-structured interviews and the benefits were directly applicable to the scope of my research. Semi structured interviews allowed me to provide a clear set of instructions to participants and enabled me to gather comparable data as broadly similar questions were asked of each participant group. The use of visual prompts was also very helpful for participants with intellectual disabilities, the Bosnian interpreters and participants. The nature of semi-structured interviews provided participants with the scope to express their opinions and experiences during a conversation which was comfortable for them. This was important given the nature of the topic of conflict which could have potentially been distressing for participants but this did not arise.

In designing the interview questions, I aimed to address the potential challenges identified by researchers working with persons with intellectual disabilities. Booth and Booth\textsuperscript{57} discuss the risks of inarticulateness, unresponsiveness to open questioning, difficulty generalising experience in abstract terms and conceptual difficulty around time when interviewing persons with intellectual disabilities\textsuperscript{58}. The interviews were designed to ascertain lived experiences and opinions so there was no abstract element to the discussions. To address Booth and Booth’s\textsuperscript{59} concerns about recounting time and dates – the questions, which were accompanied by an Easy to Read prompt sheet, followed a chronological life cycle format and did not seek exact times and dates from participants. Coons and Watson\textsuperscript{60} note that difficulties with grammar, pronunciation and uneven rates of speech are identified as typical challenges for communicating with persons with intellectual disabilities\textsuperscript{61}. In order to ensure maximum communication with participants I gave participants the option of bringing support persons to the interview to assist with communication. I ensured that the support workers did not contribute in the role referred to in the literature as a proxy\textsuperscript{62} – a person known to the participant speaking on their behalf in their absence. Hollomotz acknowledges the usefulness


\textsuperscript{58} \textit{Ibid} at pp56 – 57.

\textsuperscript{59} \textit{Ibid} at pp56 – 57.


\textsuperscript{61} \textit{Ibid}

of other subjects to contextualize the responses by the initial participant in undertaking research with persons with intellectual disabilities. Despite their usefulness in obtaining information, Hollomotz is critical of the use of proxies as it circumvents the inclusion of persons with particular communication needs. To avoid Hollomotz’ concerns, I did not use proxies in lieu of the participant’s contribution. Supporters were known to the participants through advocacy groups and were familiar with the ethos of supporting versus speaking on behalf of the individual. Supporters were present during the interview with the consent of the participants and the role of supporter was explained in advance. Consent from the participant was required before a supporter could contribute a response to a question. Supporters could rephrase a question to assist the participant to fully understand. They could also provide more context to the question for the participant to prompt a response. The need for these interjections were evident from prolonged silences by the participant or by the participant asking the supporter for assistance or clarity.

1.5.4 Qualitative research methods applied

Research in the field took place over a three-month period. The organisation of the qualitative research was determined by the practicalities involved. I needed to ensure a wide range of experiences were included in the research within a reasonable time period and considering resources for both conducting the interviews and the analysis afterward. Austin and Sutton indicate that a 45 minute interview can take up to eight hours to transcribe. Given the breadth of the discussion - the life course of adults aged over 40 and the experiences of professionals working in relevant fields - an hour was deemed necessary but often times the interviews were longer than expected. In total there was approximately 20 hours of transcription to be undertaken. Further consideration was had regarding availability of individual participants from both groups in both jurisdictions regarding schedules, location of interviews and ethical considerations. It was decided based on these factors that five participants with disabilities and five professional participants would be selected in each country, keeping in mind the need for gender balance and a diversity of experience and expertise.

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63 Ibid at p. 13.
64 Hollomotz, A., ‘Successful interviews with people with intellectual disability’, Qualitative Research (2017).
65 Extracts from interview with NILE3 and NILE4, 7 April 2016 and NILE5, 12 April 2016, transcripts on file with researcher.
67 Preliminary research indicated that interviews with members of the statutory agencies providing disability services would require a separate ethics application process for the Research Ethics Committee in Northern Ireland. This was not conducive to the timeframe of this research.
Participants in the lived experience group self-identified as having an intellectual disability and were recruited through disability rights self-advocacy groups. I approached potential participants in the professional group through the websites of their most recently known place of occupation and via the professional networking site LinkedIn. Participant information and consent forms were provided, in accessible and Easy to Read formats where necessary, to ensure they fully understood the nature of the research, the format of the interview and that their contributions would be used in a PhD thesis and subsequent academic publications by the researcher. Participants were required to be comfortable with an informal interview which would be audio-recorded. It is accepted that it is a limitation of the data that persons with diverse communication needs which could not be reflected through audio-recording could not participate. To assist during the interview an Easy to Read list of interview questions was made available during the interview which was used to varying degrees by different participants. My previous experience supporting the National Platform of Self Advocates69 equipped me with strong communication skills to conduct interviews with persons with intellectual disabilities including the drafting of materials in Plain English and Easy to Read formats.

Unresponsiveness to open ended questioning was not anticipated to be an issue as using this type of questioning contributed to more natural storytelling by the participants and ensured their comfort with the content of the conversation. However, I adjusted my approach based on responses and some participants varied between being forthcoming with answers and reluctance to speak on certain topics, such as their knowledge about the conflict in NI. For example, to ascertain whether she had an experience of violence during the Troubles in NI I asked NILE4 questions relating to emergency services70.

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68 For more information on the demographics of participants see Section 1.5.5.
69 The National Platform of Self Advocates is an advocacy organisation for adults with intellectual disabilities in the Republic of Ireland. It was established in 2012. During the establishment of the Platform support was provided by staff and students from the Centre of Disability Law and Policy at NUI Galway and other disability organisations. These supporters were referred to as the inter-agency support group, of which I was a member. I provided practical and organisational assistance for the Platform’s Committee meetings including providing materials in accessible formats and supporting the recruitment of staff for the group. <<http://www.npsa.info/history/> accessed 3 August 2016.
70 Extract from interview with NILE4, 7 April 2016, transcript on file with researcher.
Researcher: Ok, so here is kind of a harder question but you can say if you ’don’t want to talk about it. But did you ever know anyone who was involved in the Troubles?

NILE4: No, no, no.

Did you ever have any experiences with the police?

NILE4: No.

Did you ever have an accident?

NILE4: No.

Were you ever in an ambulance?

NILE4: No.

This line of questioning allowed the participant to elaborate on a particular incident if she wished but indicated that she had had no experience with emergency services or the Troubles. The short answers indicated to me that it was a topic which she did not seem interested in pursuing further. Questions were intended to guide the conversation and I adjusted the line of questioning based on responses. For example, more questions relating to conflict were asked of participants who indicated they had experience with armed forces while the level of discussion of education varied depending on the participant’s level of educational attainment.

By pursuing the lines of discussion offered by the participants I felt this increased their confidence and where supporters had knowledge they could also help the participant to answer a question more fully, but only with the consent of the participant.

1.5.5 Demographics of interview participants

The qualitative research involved two categories – five people with lived experience of intellectual disabilities and five professionals in the field of law, policy, academia, disability advocacy and services in each jurisdiction. The goal of this approach was to ensure that knowledge and experiences from each category would complement each other and provide diverse perceptions about the effect of State policies on the ground.

The first category is comprised of people who identify as having an intellectual disability. The research focuses on independent living which is a right which is more fully realised in adulthood. Participants therefore were required to have been aged at least 18 at the beginning of the escalation of the conflict in both jurisdictions. I had identified this as the late 1980s,
which was also a significant period in the timelines of each of the conflicts. Therefore participants would have been born before 1970 and lived in the jurisdiction in the years immediate to and during the conflict and until the present day. The different lengths in the conflict – 30 years in NI and 3 years in BiH – meant that the participants were at different stages of the life cycle for the pre-conflict and partially during the conflict periods. In NI the childhood years of lived experience participants would have coincided with the beginning of the Troubles whereas in BiH the participants’ childhoods coincided with the pre-conflict period. All of the lived experience participants were adults during the 1990s when the conflicts escalated and the peace processes were furthered.

I ensured gender balance within the pool of participants with lived experience, as well as a range of urban and rural participants and participants living in a wide range of residential settings. Table 1 below demonstrates the demographics of lived experience participants.

The qualitative interviews were conducted on the basis of anonymity and each participant was allocated an identifier based on their jurisdiction (Northern Ireland - NI or Bosnia Herzegovina - BIH), participant group (lived experience – LE, Professional – P), and the order of their interview (1-5). For example, the first participant from the lived experience group in Northern Ireland who I interviewed is referred to as NILE1. The first participant from the professional group in Bosnia Herzegovina is referred to as BIHP1.

Where towns, cities, organisations or services are identified these have been replaced with ‘X’ and a brief description of the place mentioned for clarity, e.g.: ‘X residential institution’. Also, I provide additional information in square brackets in order to clarify the meaning of participants from the context of the quote or to explain local dialect in the Northern Ireland contributions. All participants with a lived experience were accompanied by a support person for their interviews. Support persons contributions are recorded separate to the participants statements. The transcripts of five Bosnian interviews were verified by a translation service in Ireland for accuracy. No significant errors were highlighted. Where there was a discrepancy

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71 The Serbian Nationalist Movement was initiated by the Serbian Communist Party Leader Milosevic in 1987 in Bosnia Herzegovina. This was a significant contributing factor to the conflict to follow. HercegBosna, ‘Communist Yugoslavia: Bosnian Chronicle (1945-1991), 27 November 2009, <http://www.hercegbosna.org/eng/history/history-bih/communist-yugoslavia-bosnian-chronicle-1945-1991-8.html> accessed 3 August 2016. This period in Northern Ireland marked numerous unsuccessful attempts at a peace agreement while hunger strikers were denied political status and violence was directly targeted at British government officials, including the then Prime Minister Margaret Thatcher. ‘Soldiers Stories – Northern Ireland Conflict’, <http://www.history.co.uk/shows/soldiers-stories/articles/northern-ireland-conflict> accessed 3 August 2016.
in the original translation the most accurate version is included and the inaccurate translation discounted.

Table 1. Demographics of interview participants with lived experience.

<table>
<thead>
<tr>
<th>Demographic Country</th>
<th>Male</th>
<th>Female</th>
<th>Urban</th>
<th>Rural</th>
<th>Institutional</th>
<th>Community</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland</td>
<td>2</td>
<td>3</td>
<td>3</td>
<td>2</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>3</td>
<td>2</td>
<td>1</td>
<td>4</td>
<td>3</td>
<td>4</td>
</tr>
</tbody>
</table>

Selection of participants for the second category (professionals in the fields of disability law, policy or service provision) was largely guided by consulting with my supervisor and a NI based academic. Their suggestions were reinforced by Quinn and Degener’s report outlining the potential useful actors in an international approach to realizing the rights of persons with disabilities. This pool therefore consisted of people with professional experiences of disability law, policy and service provision ranging from academics to staff in regional and national statutory bodies and civil society organisations. A minimum of five years’ experience in a professional role in the jurisdiction was a requirement for participation. After further consultation with my supervisor, acknowledging what experiences would best

72 This reflects participants who resided in an institutional setting for all or part of their life course.
73 This reflects participants who resided in non-institutional setting for all or part of their life course.
74 I consulted with a legal and disability rights academic in Northern Ireland, about the practicalities of conducting qualitative research with people with intellectual disabilities in Northern Ireland. From this meeting I gained insight into the operation of disability services through the Department of Health and Social Services in Northern Ireland and the separate ethical approval required to interview people working directly for any government agency. This was a genuine concern for the research and it required serious consideration, recognizing my own time and resource constraints as I was still at a preliminary stage of the desk based research. Discussions during the meeting also had indicated that recruiting participants with a lived experience would be feasible given the large numbers of service organisations independent to the Department of Health.
gauge the real experience on the ground and considering the need for parity with participants in BiH I identified professionals from different backgrounds. Gender balance was achieved in this category. Table 2 demonstrates the demographics of these participants. All interviewees in the professional group came from an urban location.

Table 2. Demographics of interview participants in the professional group.

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Male</th>
<th>Female</th>
<th>Academia</th>
<th>Semi-statutory agent</th>
<th>Disability service agent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Bosnia and Herzegovina</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>4</td>
</tr>
</tbody>
</table>

Application for ethical approval required drafting of an advertisement for participants, participant information sheet, consent forms and anticipated list of questions in English language and Easy to Read format, a protocol for distress and evidence of suitability for conducting the research. Ethical approval was granted by the NUI Galway Research Ethics Committee for a period of twelve months in January 2016 and all qualitative research was completed within this timeframe.

1.5.6 Location of interviews

Interviews were held at the convenience of participants. The duration of the interviews varied between 30 minutes and 2 hours based on the time available to participants, the extent of their experiences and their communication skills. The interviews took place at locations convenient to participants in the lived experience group. Venues where persons with intellectual disabilities attended advocacy groups and evening social events were the primary location for the interviews across NI and BiH but one interview took place in the home of a participant. Table 3 outlines the location of interviews.

Table 3. Location of interviews for lived experience participants
A variety of venues were used to conduct interviews for the professional group in each jurisdiction. These were also held at the convenience of the participants and locations ranged from the participant’s place of work to Skype. Table 4, below, describes the locations of interviews. During the design stages of the interviews I had intended to conduct all of the lived experience interviews face to face but due to participant availability and time constraints one lived experience interview was conducted through video link on Skype. The participant was supported by a staff member of an advocacy group with whom he had a very positive rapport and the interview took place at the offices of the advocacy organisation. It was evident during the interview that the participant had some knowledge of English as he anticipated answers to questions and conversed briefly with me informally at the end of the interview about the experience of persons with intellectual disabilities in Ireland. The demeanour of the participant was positive throughout and from the video link he seemed comfortable and was eager to share his story of institutionalisation having recently transitioned to community living.

Table 4. Location of interviews for professional participants

<table>
<thead>
<tr>
<th>Location</th>
<th>Urban</th>
<th>Rural</th>
<th>Advocacy organisation office</th>
<th>Social activity venue</th>
<th>Participant’s home</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Northern Ireland</strong></td>
<td>3</td>
<td>2</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td><strong>Bosnia Herzegovina</strong></td>
<td>1</td>
<td>4</td>
<td><strong>2</strong></td>
<td>2</td>
<td><strong>1</strong></td>
</tr>
</tbody>
</table>

76 One of these interviews was conducted at an advocacy organisation office via Skype.
<table>
<thead>
<tr>
<th>Venue</th>
<th>Place of work</th>
<th>Suitable venue near place of work</th>
<th>Advocacy organisation office</th>
<th>Skype</th>
</tr>
</thead>
<tbody>
<tr>
<td>Northern Ireland</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Bosnia Herzegovina</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
</tbody>
</table>

1.5.7 Immersion in the field

Having grown up in a county on the border with NI I have a lot of personal experience with the history, norms and governance structures of the jurisdiction. I participated in cross border educational activities during secondary school\(^{77}\) and I am very familiar with the local dialect, turns of phrase, state institutions and localities. This contributed to a natural flow to the conversation and enriched the quality of the data gathered. I was confident availing of my own or public transport to attend the interviews.

Interviews in BiH were facilitated by a local NGO with a disability focus. As well as making suggestions for potential participants that satisfied the research requirements, this organisation translated my interview documents into the local language and provided a translator for the interviews.

During my visit I took the opportunity to become familiar with the city and take advantage of the numerous museums to deepen my understanding of how local people experienced the conflict. Most stark was the Historical Museum of Bosnia and Herzegovina\(^{78}\) that had an exhibition on ‘Besieged Sarajevo’. This included artefacts used by children and for education during the Siege of Sarajevo\(^{79}\). Having the chance to examine objects typical of the make-shift schools at the time – school books, children’s shoes and a replica of the typical living space in house basements – was extremely effective in creating a picture of the experience of


the time which was not achievable through desk based research alone. I learned even more about the conflict in Sarajevo during a tour of the city. The tour highlighted the importance of the city as the epicentre of events leading to the First World War with the assassination of Archduke Franz Ferdinand of Austria\textsuperscript{80}. The diversity of people from different religious and cultural backgrounds co-existing peacefully in the city throughout history was also highlighted during the tour\textsuperscript{81}. The idea of cultural co-existence was reinforced through the contributions from lived experience and professional participants discussed in the qualitative research later\textsuperscript{82}.

Through my host organisation, I also had the opportunity to visit persons with intellectual disabilities who were just outside of the age range required for participation in research but provided a very good example of how independent living can operate successfully in BiH. I visited a supported living service where four men lived together supported by a staff member for limited hours during the day. They were extremely interested in self-advocacy programmes in Ireland. While this experience was inadmissible for the purposes of the qualitative research it was extremely helpful in understanding the work of advocacy groups in Sarajevo and the style of independent living supports currently being provided.

I visited one of the five institutions still in operation in BiH that provides services for adults with intellectual disabilities. While the facilities were typical of total institutionalisation\textsuperscript{83} the staff there had taken the initiative to allocate part of the building as accommodation readying people to move into their communities. Users of this section of the facility were supported and equipped with the skills necessary to live independently in the near future. Literature which described institutionalisation could not convey the standards and conditions which the field work enabled me to experience first-hand and this has greatly informed my research.


\textsuperscript{82} BIHLE 1-5 and BHP1-5 all indicated the absence of sectarian related prejudices and discrimination within pre-conflict BiH. This is discussed in Chapter 4, Bosnia Herzegovina at Section 4.2.

\textsuperscript{83} Goffman, E.: ‘Asylums: Essays on the Social Situation of Mental Patients and Other Inmates’, Doubleday Anchor, New York, 1961, at p. 11. A total institution may be defined as a place of residence and work where a large number of like-situated individuals are segregated from the wider society for an appreciable period of time together lead an enclosed formally administered round of life.
1.6 Interpreters

Interpreters were used for all of the face to face interviews with Bosnian participants. Staff members of a local NGOs with a focus on disability issues provided the translation services. Participants in the professional group in BiH all used the same translator but some of the participants had some competence in English. The translator used the style of the third person instead of direct translations e.g.: ‘he/she has worked in ….’ Participants often confirmed or queried a translation and I am confident that the translations were accurate to the statements being made. I am satisfied that I had an opportunity to address my questions and to discuss any other issue that arose from their answers that deviated from the prepared questions. One interview with a professional participant did not require a translator as the participant was fluent in English and the interview took place over Skype.

The same translator that facilitated the interviews with professionals facilitated three of the lived experience interviews. Each of the other two lived experience participants had separate interpreters. Four of the lived experience translations were provided as the third person – he/she – and one translator switched between relaying information in the first and third person during the translation. While the participants with stronger communication skills had their answers communicated almost word for word, the participants with weaker communication skills and whose attention strayed from the questions asked had only the most relevant information that they relayed translated. This was due to the time constraints for the interviews I was able to verify by engaging an independent translation service to check the audio-recordings of interviews that my questions were fully answered by all participants in the lived experience group. Following the field visit, I engaged further translation services to verify the transcripts for the lived experience group of interviews to ensure that no information had been lost through the original translation. No deviation of consequence was highlighted through the verified translations and I am satisfied with the accuracy of the real-time translation.

1.7 Thematic analysis

Having considered the methods selected to organize and implement the research, the final element is to analyse the data collected. Thematic analysis of qualitative data has a wide variety of methods for implementation. The usefulness of thematic data analysis facilitating
the emergence of themes throughout interviews has been highlighted by Rubin and Rubin. Arguably the most well-known of these approaches is that set out by Clarke and Braun. While their focus is on analysis of qualitative research in the field of psychology, their six-step methodology is extremely useful to this research. The analysis will be realist or essentialist as described by Clarke and Braun which involves reporting the experiences and realities of participants, an element that is lacking from post-conflict and disability discourse in the comparative jurisdictions. I opted to make use of NVIVO, a qualitative data analysis software tool. NVIVO facilitates easier organisation of the data, while the researcher retains full control over the analysis which can be transparently scrutinized. This was important for ensuring integrity of the analysis process and for consultation with my supervisor about emerging themes.

The six step method set out by Clarke and Braun has been applied to the analysis conducted through NVIVO software.

1. Familiarisation of the data: I researched participants and arranged the interviews myself as well as conducting the interviews myself in person or through Skype. Interviews were audio-recorded and notes were taken with the permission of participants during interviews. I transcribed the interviews myself verbatim so became intimately familiar with the data. Transcripts were drafted in Microsoft Word then transferred to NVIVO.

2. Generating initial codes: Coding involved linking statements from participants that pertained to broad issues together. A brief statement explaining each code was provided for consistency and clarity. For example, where participants mentioned their involvement in activities that was organised through a service I grouped them under the code ‘Activities provided by service’. The description was ‘References to engaging in activities and events organized by disability services’ and this appeared eighteen times across nine interviews. I coded the NI interviews initially and when I

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86 Ibid. at p. 9.
88 The stages of the NVIVO analysis are collated in Appendix 1.
89 Example taken from p. 2 of the codebook generated by NVIVO software at Appendix 1.
had received fully verified transcripts of the BiH interviews, I coded these. Thirty-eight initial codes were developed across the twenty interviews.

3. Searching for themes: Once all the data had been coded, I considered how different codes contributed to emerging categories. The thirty-eight codes were reduced to eight categories. Upon further examination of the original codes broader themes emerged. These reflected the shared experiences across participants and jurisdictions under which the thirty-eight codes could be categorised. The refined eight themes are: disability services, law and policy, conflict, life experiences, comments on the research, non-government organisations, disability representation and development of country.

4. Reviewing themes: The categories identified were refined in consultation with my supervisor. Categories were redefined to better reflect the subject matter, some were merged, and some were eliminated due to lack of sufficient evidence\(^90\) or being contrary to accepted knowledge on the area.

5. Defining and naming themes: This involves structuring the themes within the data in a manner similar to what is presented in the thesis. It required in-depth description of what each theme entails, whether sub-themes are present and how it fits into the broader research question. Five overarching themes emerged. These were services during pre-conflict period, services during period of conflict, impact of peace process on disability rights, impact of UNCRPD ratification and life experiences\(^91\).

Table 5 demonstrates the process of coding for references to ‘conflict’.

\(^{90}\) References to corruption were not sufficiently repeated across the participant contributions to indicate it was a prevalent theme.

\(^{91}\) Taken from p. 14 of NVIVO Codebook at Appendix 1.
6. Producing the report: Having fully coded the data I then used the software to run queries on the data to construct the narrative alongside the desk-based research. NVIVO can provide details on the prevalence of themes between the jurisdictions which were categorized as sets, and between individuals, categorized as cases. For example, I searched for the prevalence of activities organized by disability services across conflict participants in both NI and BiH. Used in this manner, the analysis functions available through the software produce a high quality analysis to propose a solution to specific research questions.

As is evident from the method outlined, the data is deeply interrogated to ensure the themes emerging are an accurate analysis of the accounts provided by interview participants. Clarke and Braun’s approach has also been cited as a useful tool in conducting qualitative research.
in the field of intellectual disability\textsuperscript{92} and this was a very strong factor in deciding to apply their method using NVIVO software.

1.8 Problems encountered

While literature on the legislation and policies in Northern Ireland and Bosnia Herzegovina was limited, especially through the English language for Bosnian legislation, these indicated the need for further research which my PhD is addressing. Problems related primarily through the qualitative research element. I mitigated difficulties which might arise while conducting the interviews by familiarising myself with data on methods of conducting interviews with persons with disabilities and applying the best practice identified. This included ensuring equal urban-rural and gender representation and designing questions and supporting materials in Easy to Read format. However, I was conscious that even the most thorough preparations could not eliminate all potential problems. It was the first time that I had undertaken qualitative research and made use of audio recordings as well as being unfamiliar with the locations of the interviews. The ethics application process ensured that the comfort and satisfaction of participants was central to how I conducted interviews.

Lack of preparedness of two participants in the NI lived experience interviews impacted on the information obtained during the interviews. I had provided the participant information sheets in advance of the interviews but due to time restrictions the contact person at their advocacy group had not had the opportunity to explain the research to the participants beforehand to the same extent as other participants. I explained the research to the participants myself prior to the interview and ensured their consent and comfort to participate in the interviews. Support persons to the other NI interviewees had had the opportunity to discuss the content of the research beforehand so that the participants had time to consider their contributions. I feel that the hesitancy of the two individuals to discuss issues related to the conflict could have been allayed by having more time to consider the nature of the discussion. However, the personal preferences of the individuals to not go into detail of their experiences of the conflict is also indicative of the legacy of the Troubles. Their lack of confidence speaking on the topic could indicate the need for increased engagement with

persons with intellectual disabilities to ensure they are informed of events that impact their daily lives.

I found it easier to communicate with some participants than others during the interviews. For example, NILE5, took long pauses before answering my questions. He had been informed beforehand about the interview and was well supported during it. I attempted to address any miscommunication by rephrasing the questions and adding context to ensure he understood. When he did answer it was clear that he had fully understood and provided very valuable information. This was the longest interview, lasting over two hours.

There was one minor incident during the Bosnian lived experience interviews. During the incident I was concerned for the comfort of the participant as there was a large group using the same room. I asked the interviewee whether he was comfortable with other people being present when discussing potentially difficult issues of his lived experience and while he did not object to it I highlighted the need for privacy to the translator and the room was vacated without objection. The other people were not engaged with the interview process at any time.

I am conscious that I could not capture the regional dialectic richness in BiH as I could in NI. Use of colloquialisms or slang was lost due to translation. I did not specifically ask about the religious or ethnic group to which the participant belonged in either jurisdiction but it did often become clear through the conversation. Unfortunately given the restrictions of my time in Bosnia and the criteria for participants I was unable to include someone from a Bosnian Serb background. This is also due in part to the population of the cantons that I visited being predominantly Bosnian Muslim and Croat as a result of the conflict.

At the data analysis stage, an element of NVIVO software is the production of a code book – a paper trail of the coding and categorizing of the data conducted by the researcher to evidence the integrity of the analysis undertaken. The functionality of the NVIVO software was limited on my hardware and I availed of support from the company with whom I had undertaken training to rectify these limitations and to produce a codebook.

1.9 Conclusion

While there are multiple perspectives to incorporate into this research, it is evident from the discussion above that each serves a particular purpose to contribute new knowledge to the field of UNCRPD law and policy in post conflict states. Each stage of the research ensures

\[93\] This is attached at Appendix 1.
compliance with best practice in conducting research with persons with intellectual disabilities. Further it ensures that the information obtained through the desk based and qualitative research is suitable for comparative socio-legal and thematic analysis from which to extrapolate conclusions of shared issues faced by persons with intellectual disabilities, service providers, communities and states to influence policy in the future for the improvement of lives of persons with disabilities.

The next chapter will review the literature surrounding the UNCRPD and Article 19. It will discuss how the right to independent living is enshrined in other international human rights instruments, how UNCRPD and Article 19 in particular was drafted and interpretive guidance documents issued from international human rights bodies to date.
Chapter 2: Literature Review of Independent Living Movement and UNCRPD

‘Independent Living is a philosophy and a movement of people with disabilities who work for self-determination, equal opportunities and self-respect. Independent Living does not mean that we want to do everything by ourselves and do not need anybody or that we want to live in isolation. Independent Living means that we demand the same choices and control in our every-day lives that our non-disabled brothers and sisters, neighbours and friends take for granted. We want to grow up in our families, go to the neighbourhood school, use the same bus as our neighbours, and work in jobs that are in line with our education and interests and start families of our own. Since we are the best experts on our needs, we need to show the solutions we want, need to be in charge of our lives, think and speak for ourselves - just as everybody else. To this end we must support and learn from each other, organize ourselves and work for political changes that lead to the legal protection of our human and civil rights. As long as we regard our disabilities as tragedies, we will be pitied. As long as we feel ashamed of who we are, our lives will be regarded as useless. As long as we remain silent, we will be told by others what to do’.

- Adolf Ratzka.
2.1 Introduction

This chapter will examine the academic and grey literature pertaining to a social movement by persons with disabilities demanding independent living and equal participation in their communities. It is important to understand the landscape from which the rights of persons with disabilities to independent living progressed to being enshrined in an international human rights instrument. This will provide a foundation from which to assess the standards in NI and BiH in the years before, during and after the conflicts. This social movement has been motivated to affect change in the lives of persons with disabilities and this is largely why I have included qualitative research within this PhD. Legislation and policies are defunct if they do not correspond to the rights of persons with disabilities being realised in their daily lives.

The literature review will outline the nature of legislation and policies governing services which participants of the qualitative research will attest to. This indicates the universality of the segregation and rights deprivation of persons with disabilities. The Independent Living Movement set the foundations for the UNCRPD and this literature review examines both in detail. This facilitates clear understanding with the concepts of independent living, the motivations of the drafters of the UNCRPD and how the ethos of the Independent Living Movement was incorporated into Article 19.

The chapter is divided into three sections. The first section provides a brief overview of treatment of persons with disabilities by society in the recent past - the catalyst for the Independent Living Movement, originating in the United States (U.S.). This will make clear the motivation for changing the status quo of disability services, the main activists in the Independent Living Movement and their efforts to secure independent living. It will also discuss how the ethos of the Independent Living Movement was adopted in Europe. This is pertinent to the evolution of disability services in the jurisdictions which are the subject of this research.

The second section discusses the origins of the UNCRPD, the international human rights instrument which serves as the framework of assessment of the jurisdictions in this research. The section provides an overview of the discussions and efforts involved in drafting the UNCRPD. The influence of contributions by civil society organisations will also be considered.
The third and final section focuses on what the provisions contained within Article 19 UNCRPD entail. It examines whether and to what extent the right to independent living is addressed within other human rights instruments prior to the UNCRPD, the drafting process of Article 19 itself and international guidance and discussion on how it can best be implemented. This will provide clarity on what the right to independent living entails when realized. It will also ascertain the standards against which the legislation and policies relating to independent living for adults with intellectual disabilities in NI and BiH will be measured following their ratification of the UNCRPD.

2.2 Approach to literature review

This literature review was conducted in three sections, in line with the division of the sections of this chapter. The approach for the literature review remained the same for each section and there was some overlap in the materials identified for each section. For example, literature pertaining broadly to the UNCRPD often contained Article 19 specific information. Guidance was provided by my supervisor on the leading authorities in the field. The bibliographies of the academic and grey literature relating to each section were searched to guide the review also. Given the constant developments in this field, especially in relation to the information emerging from the Committee on the Rights of Persons with Disabilities, a review of the literature of Section 2 and Section 3 was undertaken periodically over the course of the research. Literature which appeared in the search relating to scientific or medical practice was discounted.

Section 1: The databases available through the library at National University of Ireland, Galway were Lexis Nexis, JSTOR, Heinonline, Taylor and Francis, EbscoHost, Pro Quest, SAGE Journals and Project Muse. I initially searched for the terms ‘historic disability services’, ‘Independent Living Movement’, ‘rights violations of persons with disabilities’, ‘institutionalisation of person with disabilities’, ‘European Independent Living’, ‘United States independent living’, ‘Ed Roberts’, ‘Judith Heumann’, ‘Centres for Independent Living’. It was also necessary to search terms historically associated with disability as the literature from the time of the Independent Living Movement did not use phrases such as ‘intellectual disability’. Searches for ‘Mental disability/ difficulties/retardation’ and ‘developmental disabilities’ were used to source the most pertinent literature, although these are not acceptable terms today. These terms were replicated in Google Scholar and finally general Google searches to capture pertinent grey literature. It became clear from the results
of the literature review of the first section that literature specific to the experience of persons with intellectual disabilities within the Independent Living Movement was lacking.

Section 2: For this section I established a Google Scholar Alert for the terms ‘UNCRPD negotiations’ and ‘United Nations Convention on the Rights of Persons with Disabilities’ to ensure I would be notified of the most up to date literature. Terms searched through the same databases as Section 1, Google Scholar and Google were ‘international disability human rights’, ‘UNCRPD criticism’, ‘UNCRPD analysis’, ‘Disability convention operation’, ‘UNCPRD establishment’. This section relied heavily on material from the Office of the High Commissioner for Human Rights, whose records include the discussions of the drafting processes and contributions by States, National Human Rights Institutions and civil society organisations of the UNCRPD, among other treaties.

Section 3: The terms searched in this section were ‘Article 19 UNCRPD’, ‘independent living’, ‘international human rights treaties’, ‘disability rights protection’, ‘community participation by persons with intellectual disabilities’ and ‘transition from institution to community’. Again the resources of the Office of the High Commissioner for Human Rights were relied upon to extract information on the drafting and discussions surrounding Article 19. Guidance information such as Concluding Observations, General Comments and List of Issues from the Committee on the Rights of Persons with Disabilities were also useful in determining the issues arising for states implementing Article 19.

2.3 Section 1

2.3.1 Definition of Independent Living

Ratzka’s definition of independent living above\(^{94}\), highlights the desire for equality between persons with and without disabilities. It acknowledges that support should be provided on terms and conditions that are directed by, and favourable to, the individual. From the multiple descriptions of independent living provided by the Institute of Independent Living it can be gleaned that ultimately the ethos and motivation behind any independent living definition are of a similar vein\(^{95}\). They encompass elements of the rejection of a patriarchal and medical approach to disability services, as well as awareness raising of civil rights issues affecting

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\(^{94}\) See p.50.

persons with disabilities, such as disproportionate unemployment and lack of representation in politics and public life\textsuperscript{96}. These concepts have been included due to historic practices and lived experiences forced on persons with disabilities by non-disabled persons in positions of authority in the provision of services.

\subsection*{2.3.2 Factors prompting the Independent Living Movement}

In any discussion of the Independent Living Movement, it is important to acknowledge that the movement emerged as a result of the historical treatment of persons with disabilities. Persons with disabilities have been the victims of egregious rights violations, including segregation, institutionalisation, violence, torture, and denial of legal recognition as persons before the law. Many of these rights violations continue to exist today.

Ferguson suggests that institutionalisation of persons with disabilities emerged during the early 20\textsuperscript{th} century due to societal opinion that placed the blame for disability on the parents. Removal of persons with disabilities to state run institutions was deemed most appropriate in that context\textsuperscript{97}. Scheer and Groce’s overview of treatment of persons with disabilities also indicates that jails and asylums were the preferred forms of institutions for persons with disabilities in many jurisdictions until the late 20\textsuperscript{th} century. They further note that lack of monitoring and oversight of these institutions indicates that human rights violations were commonplace\textsuperscript{98}. Typical characteristics of institutions which warranted an overhaul of service provision are depersonalization, rigidity of routine, block treatment and social distance. Goffman\textsuperscript{99} provides an insight into the experiences of inmates which he refers to as ‘total institution’ – every aspect of an individual’s life is organised and instructed by the administrators of an institution. While this style of services for persons with disabilities is being phased out in accordance with human rights-based approaches to service provision, Goffman’s account does serve as a reminder of the inhumane conditions of life in which persons with disabilities were detained\textsuperscript{100}.

\begin{footnotesize}
\begin{thebibliography}{99}
\bibitem{96}Ibid
\bibitem{100}This was the nature of disability services at an institution which I visited in Bosnia Herzegovina. This has been referenced at Chapter 1, Section 1.7.
\end{thebibliography}
\end{footnotesize}
During the 20th century persons with disabilities became increasingly involved in defying conceptions of themselves solely as recipients of care. One such example is that of the actions during the 1930s in New York by a collective of persons with physical disabilities. Their advocacy led to increased availability of employment positions for persons with disabilities through a government employment initiative101.

The rights abuses suffered by persons with disabilities related to every aspect of their life – their place of residence, their access to education, employment, health services, and interaction with friends, relatives and limitation on choices surrounding relationships102. Whether maliciously or benignly pursued, these actions had the effect of relegating persons with disabilities to a category of charity, from whom little could be expected and whose deviant behaviour warranted criminal sanctions rather than rehabilitation or support. Charlton’s use of the phrase ‘sick, abnormal and pathetic condition’ succinctly narrates the prevailing attitude toward persons with disabilities before the grassroots revolution, which would become known as the Independent Living Movement103. This movement emerged to challenge everything that had been denied to people with disabilities throughout history.

2.3.3 Contemporary disability history

2.3.3.1 U.S. Perspective

Shakespeare104 describes numerous factors that contributed to the development of the Independent Living Movement in the U.S. These included the American dream of self-reliance, a lack of a coherent welfare systems and labour forces, commercialism and the increasing numbers of war veterans. Ed Roberts is considered the ‘father of independent living’105. Having contracted polio as a teenager, Roberts became a wheelchair user and made use of an iron lung until mobile ventilation was available106. He was not satisfied to be

excluded from education due to the negative impact this could have on his future. McDonald and Oxford describe how Roberts was initially denied his high school diploma due to non-fulfilment of physical exercise and driving classes. Having overcome that obstacle, he was refused financial assistance, which had the potential to jeopardise his attendance at college. However, the publicity generated against the Department of Rehabilitation in California in his pursuit to have financial assistance granted resulted in the approval of his application within a week. Further prejudicial attitudes jeopardised the prospect of his admittance to the University of California, Berkeley. Although admitted as a student to Berkeley, due to lack of suitable residential quarters, accommodation was provided in the medical centre of the campus, Cowell Hall. Personal assistance was provided through a state programme, ‘Aid to the Totally Disabled’. Following Roberts’ admission, increasing numbers of students with disabilities enrolled at the college. Their group was referred to as the Rolling Quads as the members were all wheelchair users. Their successful efforts through unionisation, led to the establishment of the Physically Disabled Student Program on campus in 1970. Encouraged by this accomplishment and alongside community members who were supportive of Independent Living, the first Centre for Independent Living (CIL) was established at Berkeley in 1972. Disability activism was not isolated to the Berkeley campus. Based in New York, Judith Heumann had similar experiences to Roberts. She had contracted polio as a child. During her studies of speech and theatre at Long Island University, Heumann became involved in civil

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112 This programme was significant as there was a strong element of consumer controlled nature of the services, Roberts made decisions on who worked for him in a manner which suited his needs. Center for Independent Living, Western Wisconsin, <http://www.cilww.com/pdf/History-of-Independent-Living.pdf>, accessed 15 May 2014.
rights, anti-war and disability movements\textsuperscript{116}. This activism formed the basis in 1970 for her foundation of Disabled in Action – a disability rights protection group\textsuperscript{117}. Around the same time, Heumann applied to be accredited as a teacher to the New York City Board of Education. Her application was rejected as she was deemed to be a fire hazard as a wheelchair user. Heumann successfully litigated to overcome these discriminatory barriers against persons with physical disabilities in her pursuit of a teaching career\textsuperscript{118}.

Heumann was among the activists from all over the country who were invited to the Berkeley campus to experience what would become the basic model for all Centres of Independent Living. Rejection of the medical model, the use of advocacy, peer support and consumer control were established as the foundations of the Independent Living Movement and this disability program has acted as a template internationally\textsuperscript{119}. Batavia refers to the importance of political correctness, total rejection of the medical model and elimination of dissention among activists at the early stages of the movement in the US \textsuperscript{120}. Protests to demand adequate legislative provision and financial assistance for independent living programmes were staged. Heumann famously organized a sit-in at San Francisco’s Department of Health, Education and Welfare offices\textsuperscript{121} in 1977. Coordinated with other national protests, these resulted in the enactment of legislation prohibiting discrimination against persons with disabilities in receipt of financial assistance\textsuperscript{122}. The Independent Living Movement continued to grow from strength to strength\textsuperscript{123}.

\footnotesize
\textsuperscript{119} Pace Center for Independent Living, About, <http://pace.dreamscapesdesigners.net/about/paradigm/> accessed 12 October 2014.
\textsuperscript{122} Section 504 of the Rehabilitation Act 1973.
The most comprehensive disability rights legislation to date in the US has been The Americans with Disabilities Act 1990\textsuperscript{124}. It was modelled on the Civil Rights Act 1964\textsuperscript{125}. The ethos of the Independent Living Movement is incorporated in the American with Disabilities Act 1990 as the provision of accommodations for the needs of persons with disabilities is the primary requirement. The Americans with Disabilities Act addresses discriminatory practices in employment, education, provision of services, transportation and communications\textsuperscript{126}. These are all aspects of life that had previously been inaccessible to persons with disabilities due to physical, intellectual and social barriers. Bavaria and Shriner\textsuperscript{127} suggest that this legislation can act as both a shield against discrimination and a sword to achieve social change. This reflection of the disability movement is not surprising as activists such as Heumann were involved in the drafting of the legislation\textsuperscript{128}. However it is not without shortcomings as Shaw\textsuperscript{129} notes that the lack of consequences for non-compliance with this legislation has had a numbing effect on the benefits which this legislation could potentially provide.

\textbf{2.3.3.ii European initiatives}

John Evans\textsuperscript{130} describes the influential role which the U.S. Independent Living Movement had across the Atlantic. Although some initiatives such as anti-segregation organisations had been established, it wasn’t until the 1980s that UK activists had the opportunity to witness first-hand the CIL in Berkeley and to apply the lessons learned there to their own environments. Shakespeare\textsuperscript{131} described controversial demonstrations which took place

\begin{footnotesize}
\begin{enumerate}
\item \textsuperscript{124} Americans with Disabilities Act 1990.
\item \textsuperscript{125}United States Department of Justice Civil Rights Division, ‘Introduction to the ADA’, \texttt{<https://www.ada.gov/ada_intro.htm>} accessed 1 December 2017.
\item \textsuperscript{126}This legislation could be used to argue a right to accessible media and technology as we experience it today, over twenty years after it was drafted. Alan Scott and John Stee’s article outlines how technology and social media is impacting increasingly on our lives and can be used to support arguments in favour of fully accessible social media in order to participate in political life and current affairs. Interestingly political parties have in recent years used easily accessible material and logos in their campaigns to appeal to the masses – an inadvertent endorsement of a more accessible society from which persons with disabilities will benefit. ‘The use of popular culture and new media in parties and social movements. From Media Politics to E-protest’ Information, Communication and Society (2000) Vol. 3, Iss. 2, 215-240.
\item \textsuperscript{128} Independent Living USA, ‘Judith E. Heumann, Assistant Secretary, Office of Special Education and Rehabilitative Services’, \texttt{<http://www.ilusa.com/articles/0223021judith_heumann.htm>} accessed 15 May 2014.
\item \textsuperscript{131} Shakespeare, T., ‘Disabled people’s self-organisation a new social movement?’ Disability, Handicap and Society, (1993) Vol. 5, Iss. 3.
\end{enumerate}
\end{footnotesize}
during this period in the UK, such as activists chaining themselves to buses to highlight inaccessible public transport. Finkelstein and Wilkins suggest that the Independent Living Movement in the UK focused on the transition to independent living for persons living in institutions rather than the establishment of suitable accommodation on university campuses. In this way it could be argued that the UK movement has been targeted at the masses of persons with varying disabilities from the very start, whereas only those availing of college education were involved with the early stages of the movement in the US.

The designated UN International year of the Disabled Persons in 1981 served as a rallying point for a group of persons with disabilities in Hampshire, England. ‘Project 81’ was established as a scheme to move persons with disabilities from institutions to independent living. It involved negotiating financial packages with their local authorities who were funding their institutionalisation. Support and financial assistance for the movement had to be negotiated through an existing social welfare and healthcare system involving charities, local government and national government. As was evident from the discussion on the experience of advocates in the US, their movement involved the highlighting of disability issues to a society and a system which was wholly unfamiliar with their needs. The existing system in the UK, where funding followed the institution and not the individual, was deemed appropriate by policy-makers and was subject to little criticism from bureaucrats. Disability activists incorporated the ethos of socialism in their advocacy. While the UK performed well economically, they opined that the incorrect use of resources relegated persons with disabilities to segregated institutions and piecemeal education and employment opportunities. The economic policy of the time of encouraging market competition was favourable to the UK Independent Living Movement as local authorities were persuaded to provide payments directly to residents of institutions with disabilities.


\[133\] Ibid

\[134\] Ibid


\[136\] Ibid

\[137\] British Broadcasting Corporation, ‘History: Margaret Thatcher; From grocer’s daughter to Iron Lady’, <http://www.bbc.co.uk/history/people/margaret_thatcher> accessed 15 May 2014

The Hampshire CIL was established in 1984, the first CIL in the UK. Residents of disability institutions co-ordinated themselves, establishing a think-tank to continue the momentum of the Independent Living Movement. Derbyshire became the second CIL in the UK. The approaches of the two centres varied, both with their own advantages, based on the experiences and strengths of their founders. The publication of the Derbyshire Seven Basic Needs\textsuperscript{139} represented the ethos and beliefs on independent living for persons with disabilities and built largely on the concepts from the US movement. These built on the core concepts which the advocates had experienced at Berkeley CIL and encompass housing, personal assistance, mobility assistance, accessible design, peer support, information and assistive technology with adequate support to utilise it\textsuperscript{140}.

The British Council of Disabled People (BCODP) was established in 1981 to act as the umbrella body of disabled persons’ organisations, which were emerging throughout the UK\textsuperscript{141}. The BCODP ensured that a powerful, well-organized face of the movement was posed in front of, and poised against, the government and public when negotiation and awareness raising campaigns were being pursued. Among the important work done by the BCODP was the commission of research in 1989 based on the discrimination experienced by persons with disabilities\textsuperscript{142}. Previous research had been funded by parties who prescribed to a medical model or who engaged in a purely academic approach. This step toward what Oliver referred to as ‘emancipatory research’\textsuperscript{143} led to a marked change in academic and professional research which began to favour the social model of disability.

The ethos of Independent Living was also embraced across Europe. European networking was a vital aspect of the UK Independent Living Movement\textsuperscript{144}. This was further strengthened

\textsuperscript{139} These were comprised of information, peer counselling, housing, technology, personal assistance, transport and access. The Seven Basic Needs were then expanded to twelve in 1989 by the Hampshire Centre of Independent Living to include advocacy employment, education, income/benefits and appropriate healthcare provisions. Centre of Independent Living Kent, ‘Twelve Basic Needs’, <http://www.cilk.org.uk/basicneeds.htm> accessed 14 March 2014.


\textsuperscript{141} UK Disabled People’s Council, ‘About Us’, <http://www.ukdpc.net/ukdpc/pages/who.php> The BCODP is now known as the UK Disabled People’s Council See also, Barnes, C., ‘What a difference a decade makes: reflection on doing ‘emancipatory’ disability research’ Disability and Society (2003), Vol. 18, No. 1, pp3-17.

\textsuperscript{143} The National Disability Authority and The Centre for Disability Studies ‘Emancipatory Research: A vehicle for social transformation or policy development’, 1\textsuperscript{st} Annual Disability Research Seminar, University College Dublin, 3 December 2002.

\textsuperscript{144} This aspect of their work continues to been influential on the establishment of regional self advocacy groups in the U.K, Ireland and throughout Europe.
by collaboration between European and American activists at the first international conference on independent living in Munich in 1982. However it was the connections between the UK and Sweden that would prove pivotal in the formal establishment of a European Network on Independent Living. The champion of independent living in Sweden during the 1970s and 1980s was Adolf Ratzka. Despite Sweden’s policies of wealth distribution, facilities and services for persons with disabilities were out-dated. Ratzka was motivated to implement independent living in Sweden having studied in California. He utilized his scholarship funds to employ fellow students as personal assistants during the late 1960s and 1970s. After a conference in Stockholm in 1983, which Ed Roberts addressed, the Stockholm Cooperative on Independent Living was established. This group aimed to introduce personal assistance services as the norm for persons with disabilities. However, like the U.S. and UK experiences, it was not without its critics and obstructions. Some hostility towards the campaign came from persons with disabilities who were not satisfied to make the change to such a radical new form of support service. By 1989 however a programme of personal assistance was accepted and implemented at a mainstream level in Sweden.

Evans notes that the founders of the CILs at Derbyshire and Hampshire made considerable contact with Ratzka as the first Swedish CIL was being established and there was much learning exchanged through well attended conferences.

Another European initiative which contributed to the further development of Independent Living programmes was the HELIOS II programme. This programme conducted research around social integration and removal of barriers in society in European Union (EU) Member States in order to identify innovations and best practices and create a pan-European strategy.

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149 Ibid
150 Ibid
on inclusion for persons with disabilities\textsuperscript{151}. From 1993 to 1996 HELIOS II supported dissemination of information on locally based initiatives and information was gathered from the implementation of projects providing personal assistance and direct payments\textsuperscript{152}.

The culmination of the initiatives, lobbying and activism described in the above literature was referred to by the Disability Rights Commission as:

‘[A]ll disabled people having the same choice, control and freedom as any other citizen - at home, at work, and as members of the community. This does not necessarily mean disabled people 'doing everything for themselves', but it does mean that any practical assistance people need should be based on their own choices and aspirations.’\textsuperscript{153}

This definition is extremely useful for this discussion. Jenny Morris asserts that independent living is motivated by three basic principles\textsuperscript{154}. The first is equality of applicability of civil and human rights to persons with disabilities\textsuperscript{155}. The second is that historically the treatment of disabled persons has violated and undermined their rights and finally that this treatment does not flow naturally by virtue of having a disability\textsuperscript{156}. This third principle captures the motivation of the original Independent Living Movement activists. It challenges the automatic exclusion from participation in society based on disability\textsuperscript{157}. Regardless of the origin of disability – from birth or acquired - the denial of accessibility to a wide variety of facilities and services in the community arises because of unsuitable physical, social and cultural infrastructure\textsuperscript{158}.

\textbf{2.3.4 Critiques of the Independent Living Movement}

As discussed above, the main actors accredited with the progress acquired through the Independent Living Movement are persons with physical disabilities. De Jong has highlighted that while the Independent Living Movement has made visible the sentiments of persons with

\textsuperscript{154} \textit{Ibid}
\textsuperscript{155} \textit{Ibid}
\textsuperscript{156} \textit{Ibid}
\textsuperscript{157} \textit{Ibid}
\textsuperscript{158} \textit{Ibid}
disabilities, he is critical of the emphasis on obtaining individualized funding to direct services as a consumer. He suggests that this ignores the environmental factors creating obstacles to full inclusion in society for persons with disabilities. Further, DeJong acknowledges the impact of other rights movements such as the civil rights movement and consumerism on the success of the Independent Living Movement\textsuperscript{159}. Williams notes the impact of rehabilitation professionals who were supportive of devising new national policies and legislation\textsuperscript{160}. Williams also notes that the origins of the ILM on a college campus created a bias towards youth with disability\textsuperscript{161}.

Tatlow-Golden et al, note the role of litigation by parents in the U.S. against institutionalisation of their children with disabilities. Along with the uncovering of scandals within institutions and the cost of institutionalisation these factors contributed to the progression towards community living initiatives for persons with intellectual disabilities\textsuperscript{162}. The reliance by persons with intellectual disabilities on others for advocacy is also described by Hillman et al\textsuperscript{163}. This is reinforced by Dimopolous who argues against assumptions that initiatives which benefit persons with physical disability will automatically benefit persons with intellectual disabilities\textsuperscript{164}.

Despite the equal applicability of the ethos of the Independent Living Movement to the situation of institutionalised persons with intellectual disabilities, very limited literature is available on the topic. Pfeiffer is critical of the exclusion of the movement for persons with intellectual disabilities in literature\textsuperscript{165}. This is surprising given the contributions of CILs to the literature in this field and the cross-disability nature of their services\textsuperscript{166}. Heumann described the wide range of disabilities which were represented at anti-discrimination protests. This included persons with ‘developmental’ disabilities attending protest sit-ins at

\textsuperscript{159} DeJong, G., Independent Living: From social movement to analytic paradigm’, Archives of Physical Medical Rehabilitation, 1979.
\textsuperscript{161} Ibid
\textsuperscript{166} Ibid
regional government offices\textsuperscript{167}. Ward and Meyer suggest that much of the Independent Living Movement involved persons with physical disabilities realising themselves, and convincing others, that they are capable of making their own decisions and exercising choice over their own lives\textsuperscript{168}. Where the Independent Living Movement gained momentum from activists who were skilled at vocalising their rights and how to achieve them, persons with intellectual disabilities first had to acquire skills to advocate for themselves. Because of this persons with intellectual disabilities capitalising on the movement towards independent living was delayed. Ward and Meyer highlight the role of persons with ‘developmental’ disabilities in the progress of self-advocacy as a movement, encapsulated in the People First movement which developed alongside but separate to the Independent Living Movement\textsuperscript{169}. While self-advocacy was used as tool for the realisation of civil rights of persons with intellectual disabilities it did not focus specifically on independent living and was focused on the individual rather than a larger societal level which is the subject of this research.

\textbf{2.3.5 Conclusion}

Exercising choice and control over daily life is evident as a core component of the Independent Living Movement. Collaboration across countries and continents has proven extremely effective in the development of independent living and personal assistance programmes. This demonstrates the universality of the ethos of the Independent Living Movement. Pooling of finances, information, policies and technological advances were identified from early on in the Independent Living Movement as crucial to the success of the advocates efforts. The social and cultural upheavals in which the Movement took place was influential on its success – in America the focus on non-discrimination and civil rights provided a vehicle for Roberts and Heumann, among others, to ensure persons with disabilities were not excluded from legal and social change. While such radical changes were not experienced across the Atlantic, the emergence of the EU provided a mechanism for the collaboration of activists. The Independent Living Movement is in no way complete but lessons have been learned and are informing future actions by activists and policy makers alike. The review of the literature pertaining to the Independent Living Movement has


\textsuperscript{169} \textit{Ibid}
clarified the impact of the discrimination against persons with disabilities and the logical initiatives and interventions which resulted in regaining independence, choice and control in the lives of the persons involved. It has highlighted what independent living entails and the legislative and policy measures which were effective in realising the aspirations of the activists. While the bulk of the literature on the Independent Living Movement relates to events in the US, the issues being rallied against persist internationally and the principles of the Movement can be adapted to the circumstances of any person with a disability. As this research is examining post-conflict countries this literature review has highlighted that states experiencing social upheaval could draft and implement independent living legislation and policies to some degree of success in the earliest stages of the Independent Living Movement.

2.4 Section 2

2.4.1 UNCRPD Literature Review

This section will provide an overview of the international human rights monitoring system before turning specifically to literature on the UNCRPD. The UNCRPD provides a framework for the realization of human rights for persons with disabilities. It recognizes the exclusion from the enjoyment of basic rights which persons with disabilities have been subjected to as can be seen from the previous section. The UNCRPD seeks to clarify the applicability of the International Bill of Rights in a disability compliant manner. The UNCRPD is concerned with the realization of rights of civil, political, economic, social and cultural rights for persons with disabilities in their daily lives through appropriate resource allocation and policy implementation by States party to the Convention. The Independent Living Movement had the same aim of affecting change for the individual in how they directed their life and interacted with their communities. States that have ratified UNCRPD, including NI (through UK ratification) and BiH, commit to adhering to the obligations set out within the UNCRPD. In order to understand the scope of state obligations under UNCRPD, and how these might apply to post-conflict states, I undertook this literature review. Prior to exploring the specific obligations under Article 19, it was important to gather insights on the content of the UNCRPD as a whole, its contributions to the further development of human rights law, and its general interpretation, as well as literature on its limitations and challenges in implementation. Scholarship on these issues would help me to assess whether the states in my study could fully meet their obligations.
Four themes emerged during this research and this review will be divided into 1) Applicability of existing human rights instruments, 2) Grounds for a disability specific convention, 3) Drafting process and operation of the convention, and 4) Criticisms and future potential of the UNCRPD.

2.4.2 Applicability of previous human rights instruments to disability rights

The United Nations is an international collaboration body established in 1945 for the promotion and protection of human rights, peace keeping, economic and environmental sustainability and counter terrorism\textsuperscript{170}. The original international human rights instrument, the Universal Declaration on Human Rights (UDHR) was drafted after the World War II as an attempt by the international community to prevent the atrocities of that conflict from reoccurring\textsuperscript{171}. The UDHR created a baseline of fundamental human rights and efforts were made to ensure it did not solely reflect a Western notion of human rights\textsuperscript{172}. The only provision which makes direct reference to disability in the UDHR is Article 25.1\textsuperscript{173}. It asserts that everyone is entitled to a decent standard of living and to security in the event of disability.

The UDHR was later supplemented by the International Covenant on Civil and Political Rights (ICCPR) and the International Covenant on Economic, Social and Cultural Rights (ICESCR)\textsuperscript{174} and the three instruments together formed the International Bill of Rights. Since then the United Nations have drafted human rights instruments with a focus on specific groups. These include the Convention on the Rights of the Child\textsuperscript{175}, the Convention on the Elimination of All Forms of Discrimination Against Women\textsuperscript{176} and the Convention on the

\textsuperscript{172} Ibid
\textsuperscript{173} Universal Declaration of Human Rights, Article 25
\textsuperscript{176} Office of the High Commissioner of Human Rights, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CEDAW.aspx>
Elimination of All Forms of Racial Discrimination. Schulze describes the inadequate protection afforded to persons with disabilities who were consistently relegated to a savings clause within broader human rights instruments.

All United Nations instruments are clear about the non-discriminatory nature of their applicability to all persons equally. The failure to include disability in the texts of the ICCPR and the ICESCR could be argued as a contributory factor of the failure of states to approach and implement human rights policies inclusively. However, the Treaty Monitoring Bodies have offered some interpretations of these covenants which can be applied to the disability sphere. General Comment No. 5 of the Committee on Economic, Social and Cultural Rights describes disability based discrimination as any action nullifying the enjoyment of economic, social and cultural rights. The General Comment identifies housing, education, employment and transport as areas which experience highest levels of discrimination for persons with disabilities. No disability specific General Comment has been drafted by the Human Rights Committee, the monitoring body of the ICCPR, but the equality and non-discriminatory nature of the applicability of the existing General Comments make them applicable to persons with disabilities. Megret is critical of the exclusion of disability as a ground for discrimination expressly formulated in the ICCPR and that the Human Rights Council did not take the opportunity to rectify this at a later stage.

Article 16 of the UN Convention Against Torture, Cruel, Inhuman and Degrading Treatment (UNCAT) prohibits public officials from committing or instigating acts of cruel, inhuman

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177 Office of the High Commissioner of Human Rights, <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CERD.aspx>
179 Committee on Economic Social and Cultural Rights General Comment No. 5: Persons with Disabilities, <http://www.refworld.org/pdfid/4538838f0.pdf>, accessed 4 April 2014, para 15. ‘For the purposes of the Covenant, ‘disability-based discrimination’ may be defined as including any distinction, exclusion, restriction or preference, or denial of reasonable accommodation based on disability which has the effect of nullifying or impairing the recognition, enjoyment or exercise of economic, social or cultural rights. Through neglect, ignorance, prejudice and false assumptions, as well as through exclusion, distinction or separation, persons with disabilities have very often been prevented from exercising their economic, social or cultural rights on an equal basis with persons without disabilities. The effects of disability-based discrimination have been particularly severe in the fields of education, employment, housing, transport, cultural life, and access to public places and services.’
180 Ibid
182 United Nations Convention Against Torture, Cruel, Inhuman and Degrading Treatment, Article 16
and degrading treatments. Even though there is no specific reference to disability within UNCAT, as institutions for persons with disabilities are state run Article 16 can be applied to the experiences of those institutionalised. The inclusion of disability as a ground of discrimination in the Convention on the Rights of the Child under Article 2 is positive. UNCRC goes further to specifically identify the rights of children with disabilities under Article 23. This indicates a prioritization of disability as an issue warranting increased awareness among states.183

Waterstone184 and Verdugo, Navas, Gomez and Schalock185 outline the international ‘soft law’ protections afforded to persons with disability before the entry into force of the UNCRPD. While previous human rights instruments were applicable to all persons equally, some disability specific instruments had been developed before the UNCRPD. These are the Declaration on the Rights of the Mentally Retarded (1971)186, the Declaration on the Rights of Disabled Persons (1975)187, World Programme of Action concerning Disabled Persons (1982)188, Tallin Guidelines for Action on Human Resources Development in the Field of Disability (1990)189 and the Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care (1991)190. General Assembly Resolution 48/96 mandating the Standard Rules on Equalization of Opportunities for Persons with

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1. Each State Party shall undertake to prevent in any territory under its jurisdiction other acts of cruel, inhuman or degrading treatment or punishment which do not amount to torture as defined in article 1, when such acts are committed by or at the instigation of or with the consent or acquiescence of a public official or other person acting in an official capacity. In particular, the obligations contained in articles 10, 11, 12 and 13 shall apply with the substitution for references to torture of references to other forms of cruel, inhuman or degrading treatment or punishment.’

Disabilities is an example of the pre-existing protections available, but Waterstone is critical that no explicit reference to disability was included in the Millennium Development Goals.

Schulze outlines the regional development of disability protection in the run up to the formulation of the UNCRPD which includes the 1988 Additional Protocol to the American Convention on Human Rights, 1999 Organisation of American States Inter-American Convention on the Elimination of All Forms of Discrimination Against Persons with Disabilities, Article 26 of the European Union Charter on Fundamental Rights and Article 18 of the Banjul Charter on Human and People’s Rights. Stein asserts that despite international awareness of persons with disabilities as a group being vulnerable to human rights violations. Initiative such as the International Year of Disabled Persons 1981 and

195 Article 18, stating ‘Everyone affected by a diminution of his physical or mental capacities is entitled to receive special attention designed to help him achieve the greatest possible development of his personality. The States Parties agree to adopt such measures as may be necessary for this purpose and, especially, to: a. Undertake programs specifically aimed at providing the handicapped with the resources and environment needed for attaining this goal, including work programs consistent with their possibilities and freely accepted by them or their legal representatives, as the case may be;
b. Provide special training to the families of the handicapped in order to help them solve the problems of coexistence and convert them into active agents in the physical, mental and emotional development of the latter;
c. Include the consideration of solutions to specific requirements arising from needs of this group as a priority component of their urban development plans;
Encourage the establishment of social groups in which the handicapped can be helped to enjoy a fuller life.’
197 Article 18.4, African Charter on Human and People’s Rights. ‘The aged and the disabled shall also have the right to special measures of protection in keeping with their physical or moral needs.’ <http://www.achpr.org/files/instruments/achpr/banjul_charter.pdf> accessed 3 November 2017.
Decade of the Disabled during 1982-1991 have not prevented persons with disabilities continuing to be excluded from mainstream human rights protections.

2.4.3 Grounds for a disability specific convention

Had the previous international human rights instruments been implemented as intended – in a non-discriminatory way to all persons – it would not be necessary to specify how civil, political, economic, social and cultural rights relate to persons within minority groups. However, as highlighted by the literature, this implementation did not occur for persons with disabilities. Jolly welcomes the drafting of UNCRPD as recognition of this inequality in human rights enjoyment by the foremost international human rights forum\(^{199}\). She argues that the unequal and non-applicability of existing human rights instruments to persons with disabilities suggests a severe lack of understanding of the requirement for rights protection and promotion to be adaptable to disability specific issues.

This is also addressed in compelling arguments by Quinn and Degener’s report for the Office of the High Commissioner on Human Rights\(^{200}\). It provides an analysis of the operation of existing human rights instruments when applied to persons with disabilities and their results formed the bedrock of a strong argument in favour of the creation of the UNCRPD. Chapter 13 of their report outlines the then recent progresses in support of an international disability based treaty. The World NGO Summit in March 2000, at which many DPOs were in attendance, resulted in the Beijing Declaration on the Rights of Persons with Disabilities in the New Century. This outlined the support to work toward a Disability Rights Treaty\(^{201}\).

Megret reiterates that it was the non-universal application of previous human rights instruments which led to the necessity of a specialised disability convention\(^{202}\). He also claims that the shortcomings of the other instruments affected persons with disabilities so much that a complete overhaul to the manner in which the Convention is formulated, from involvement of NGOs to the more detailed, almost instructive, provisions included\(^{203}\). The


\(^{203}\) Ibid at p. 504.
response to the gap in protection of rights for persons with disabilities is much more than a gesture of political good will but Megret stressed that no new rights are created, despite first appearances\textsuperscript{204}. He argues that rather than introducing new rights, the CPRD affirms, reformulates, and extends existing rights to persons with disabilities\textsuperscript{205}. The convention affirms existing rights and provides that they are directly applicable to persons with disabilities. This is important for persons with disabilities who encountered a denial of their rights in practice, despite being guaranteed them theoretically. The UNCRPD reformulates certain rights by providing increased levels of detail which aims to guarantee the achievement of these rights. This is a response to the requirement to outline appropriate measures to be taken in order to prevent re-occurrence of rights violations.

2.4.4 Drafting process and operation of the convention

The process for the creation of the UNCRPD was initiated by Mexico in 2001 when the General Assembly adopted a resolution to consider a disability specific convention\textsuperscript{206}. An Ad Hoc Committee was established as the forum from which the Convention would be discussed, debated and finalised over eight sessions \textsuperscript{207}. Membership of the Ad Hoc Committee was open to all United Nations member states and observers and the contributions of NGOs were also permitted\textsuperscript{208}. A draft text of the Convention was prepared by a specialised working group for deliberation which was first presented at the third session\textsuperscript{209}.

The mantra of ‘Nothing About Us Without Us’ emerged during negotiations of UNCRPD, demanding the involvement of persons with disabilities in the development of policy and legislation\textsuperscript{210}. The role of civil society organisations was also a new feature of the

\textsuperscript{204} Ibid at p. 505.
\textsuperscript{205} Ibid at p. 507.
\textsuperscript{207} UNCRPD India, <http://uncrpdindia.org/about/history/> accessed 8 February 2014.
negotiation of the UNCRPD, which other human rights treaties were not subject to, to such an extent at least. Woodburn identifies the UNCRPD as heralding a new level of NGO and policy maker co-operation. Woodburn describes this increased involvement as a by-product of public disenchantment with political parties. Woodburn argues that NGOs have responded to this by fulfilling roles which states are not fulfilling at all, or inadequately so. Woodburn also asserts that states are partly responsible for increased NGO involvement. Lacklustre political and legislative initiatives prompted organisations with experience and motivation in the disability arena to demand increased participation in negotiations. This in turn resulted in the establishment of the International Disability Caucus, comprised NGOs and Disabled Person’s Organisations (DPOs). Kayess and French welcome this NGO involvement and recount the role of UK disability activists during the 1970s in shifting the focus from individuals to society. The drafters of the UNCRPD wanted to ensure that disability would retain features of an evolving concept. This would allow for state flexibility as disability can arise in many forms unique to certain environments. It is also suggested that this flexibility could lend itself to the inclusion of rights protection for those with short term disabilities.

2.4.5 Monitoring UNCRPD

Cole opines that international human rights treaties can be perceived as exercises in positive international relations without any repercussions for digressions on behalf of the state. Turner asserts that incorporation into the laws of sovereign states is the only way to prevent international covenants becoming unenforceable rhetoric. These criticisms of international human rights treaties in general have contributed to the eagerness to completely

slogan has its origin in the South African disability rights movement. Whatever the origin of the phrase, it is a direct result of the disability rights movements which began with the establishment of the Center for Independent Living at Berkeley, California in 1972 as discussed earlier in this chapter.

Woodburn, H, ‘Nothing about us without civil society: The role of civil society actors in the formation of the UNCRPD’ Political Perspectives (2013) Vol. 7, Iss. 1, pp 75-96.

Ibid


Ibid


understand the usefulness of our most recent human rights mechanism\textsuperscript{218}. As such the monitoring of UNCRPD will be extremely important to ensure it avoids the pitfalls of lack of implementation as other human rights instruments.

Article 33 of the UNCRPD provides for the monitoring of State adherence to this Convention. Article 33 necessitates the establishment of a national focal point and allocates powers to organisations representing persons with disabilities to participate in state policy formation on disability issues\textsuperscript{219}. During the negotiation of the UNCRPD it was hoped that the monitoring mechanism chosen at international level would avoid the shortcomings, such as late reporting by states, that other UN Treaty Monitoring Bodies had experienced, but time constraints limited the potential for innovation in this aspect\textsuperscript{220}. Ultimately, the UNCRPD established the same kind of treaty monitoring body as other human rights treaties, known as the Committee on the Rights of Persons with Disabilities. States are required to submit a report within two years of ratification of the Convention and every four years after that or upon request\textsuperscript{221}. While the ratification to the Convention only limits the state obligation to those discussed above, ratification of the Optional Protocol extends the reach of the Committee. A number of resources are at the disposal of the Committee to encourage timely reporting and to fill the void where states have been non-compliant in this regard which involves the request of the expertise of NGOs, DPOs and specialist agencies within the state through shadow reporting. Stein and Lord outline alternative potential monitoring solutions which were considered during the drafting process but ultimately not adopted. However, they acknowledge the uniqueness and importance of the use of the Conference of States under Article 40\textsuperscript{222}. Usually a Conference of States meet to discuss technical issues but under the UNCRPD this has served as an opportunity to assess implementation and promote dialogue among participants. The current modus operandi for the UNCRPD Committee is the


examination of states on a determined cyclical basis. Koch argues that a national monitoring body, such a sufficiently resourced focal point, is one method of discharging the states duty to self-regulate as well as the courts and judiciary having a role in the monitoring of UNCRPD compliance. At a national level NHRI’s have been suggested as appropriate focal points for UNCRPD monitoring, either as an independent mechanism or combined with other national agencies, including DPOs but the cooperation between State and NHRI will vary greatly internationally.

2.4.6 Criticisms and future potential of the UNCRPD

As the first international human rights instrument to be conceived, drafted and developed during the twenty first century, the UNCRPD has attracted much commentary and analysis from academics, non-government organisations and disability activists.

Doron and Apter note the arguments against the need for a specific convention on the rights of older persons while acknowledging that the drafting of UNCRPD paved the way for older persons as the next group to be subject to a thematic convention. The determination of the UNCRPD as an effective tool in the protection and promotion of rights of persons with disabilities has the potential to influence the current discourse on a Convention aimed at the rights of older persons. Stein acknowledges that the practical aspects of rights protection and the fulfilment of one right can be largely dependent on available connecting factors, e.g.: the right to work is contingent on the availability of suitable vocational training and accessible transport among many others.

The language used in the text of the UNCRPD is extremely important. Members of the EquitAble Consortium formulated a scoring system (Equiframe) of texts of human rights


mechanisms\textsuperscript{228}. Equiframe is used to assign marks based on the success of the texts to explicitly protect the rights of persons with disabilities. Equiframe highlights that inconsistencies in the translation and interpretation of phrases could lead to lapses of and unequal application and enforceability of UNCRPD provisions on a regional, or even state by state basis. This became clear during the application of UNCRPD in Austria when the German translations were found to be inaccurate by Inclusion Europe\textsuperscript{229}. Although the UNCRPD experienced a speedy negotiation process\textsuperscript{230} the lengthy discussion at negotiation stages and the significance of the alterations made during this period as a result of civil society contributions is indicative of the importance of phrasing to states\textsuperscript{231}.

Hendrick is critical of the lack of definition of disability within the Convention\textsuperscript{232}. He claims that the balancing act between medical and social approaches which medical practitioners would be forced to engage in could jeopardise consistent human rights protection. He is also defensive about the paternalistic care system and states that insufficient consideration is given in the UNCRPD to the benefits of medical based advances can make to persons with disabilities\textsuperscript{233}.

Meekosha and Soldatic\textsuperscript{234} argue that monitoring and reporting is extremely resource intensive for all parties involved and coupled with the fact that some states do not completely support treaties to which they are a signature, creates an environment of hostility toward international rights protection efforts, when little impact is visible at grassroots level.


\textsuperscript{233}Ibid

Verdugo, Navas, Gomez and Schalock’s discussion of the UNCRPD assesses the provisions as they relate to eight core Quality of Life indicators. These indicators have developed over the last thirty years and have evolved to become a guide for programmes and policies as well as a useful yardstick to measure actual achievement of the rights contained in the UNCRPD. While the usefulness of quality of life indicators as an assessment of standards of care has been heavily criticised as potentially reinforcing an environment of institutionalisation, the authors’ discussion indicates that as similar measures can be applied to other groups, such as older persons, the aged, increased specialised human rights protection could be feasible in the future. These authors suggest that the UNCRPD has been successful to some extent among medical practitioners to re-conceptualise their role in supporting persons with disabilities and to extend these enlightened policies to other areas of their work.

Ollerton and Horsfall’s research investigated the utility of the UNCRPD to promote the right to research for persons with intellectual disabilities. It was prompted by the reporting by DPOs of a negative attitude toward persons with disabilities in Australia. By involving persons with intellectual disabilities to highlight the lack of accessibility of a wide variety of public amenities and services, and therefore a breach of their UNCRPD rights, technology and assistive devices were successfully used to perform research which was then communicated to, and positively received by, relevant public office holders.

Hammarberg asserts that while the UNCRPD does reaffirm the legality of existing rights and their applicability in a disability context, the continuation of practices for children and adults with disabilities- in particular persons with intellectual disabilities- such as institutionalisation in prison like conditions, indicates the disconnect between the UNCRPD and the experiences on the ground. However on a positive note, the author is enthusiastic.


238 Ibid

239 Ibid

about the potential of universal design to ensure current and future public services are fully accessible and highlights the evolution of disability service providers to incorporate human rights principles.

Stein and Lord\textsuperscript{241} consider the CPRD to have the potential to recast disability as a social construction and to respond to disability specific issues which impede the enjoyment of rights within mainstream policies. Stein and Lord also suggest an invigorative use of the Conference of State Parties, looking towards the operations of similar environmental monitoring mechanisms\textsuperscript{242}. Despite the authors’ concerns about the lack of a regional dimension to monitoring and implementation, the success of the Convention on Rights of the Child in the collaboration with UNICEF is highlighted and the scope for similar action by the Committee on the Rights of Persons with Disabilities is discussed.

The United Nations has also provided guidance for politicians on the UNCRPD. The guidance suggests establishing bodies within each state tasked with reviewing existing legislation, suggesting necessary amendments or edits to new legislation being drafted is crucial to include exact wording from the Convention in order to ensure the highest possible standards of rights protection domestically\textsuperscript{243}.

### 2.4.7 UNCRPD Literature Review Conclusion

In conclusion, the literature available on the UNCRPD, strongly indicates that while no new rights have been created in the treaty, it is a significant step in the direction of the actual achievement of previous unenforced rights provided to persons with disabilities internationally. Non-government and representative organisations for persons with disabilities have been extremely influential in the development of the actual document as well as in the implementation of policies and programmes formulated since the UNCRPD has come into force. Despite differences in opinion among academics on the most useful approach for states to take in the observance and monitoring of their UNCRPD obligations, a common theme of equality of persons with disabilities has emerged.


2.5 Section 3

2.5.1 Article 19 UNCRPD Literature Review

This discussion will now focus on the provision of the UNCRPD upon which this research is based. As the UNCRPD does not confer new rights on persons with disabilities there are examples of independent living being provided for in human rights instruments which preceded the UNCRPD. This section examines the rights protected through existing human rights instruments which encompass elements of the right to independent living. There is a lot of repetition of the nature of these rights across multiple human rights instruments but this strengthens the claim to these rights for persons with intellectual disabilities.

2.5.1.i Universal Declaration of Human Rights

There are multiple provisions within the UDHR, beyond the provision of equality and non-discrimination which pertain to the right to independent living for persons with disabilities244. The right to non-interference with the home (Article 12) has relevance to the continued residential and institutional nature of services for persons with disabilities. As persons with intellectual disabilities might require more support than non-disabled persons to travel internationally, the right to freedom of movement245 and to take up residence within state borders is important (Article 13). Participation in public life and services (Article 21) and the right to an adequate standard of living (Article 25) are very pertinent to independent living for persons with intellectual disabilities. Recognition of the right to cultural life (Article 27(1)) and to contribute to the community and development of personality (Article 29 (1)) are also elements reflected in Article 19 UNCRPD.

2.5.1.ii ICESCR

Article 11 of ICESCR promotes the right to an adequate standard of living and continuous improvement of conditions246. States can fulfil this obligation by ensuring that independent living programmes are resourced and implemented in a manner which ensures the standard of living which persons with disabilities enjoy is not reduced following transitions from

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institutions to community living. Article 15 focuses on the right to benefit from advancements in technology and science. Availing of technology and providing support to use technology was a feature of the Seven Basic Needs identified by UK disability advocates\(^{247}\) during the 1980s to enable individuals to increase their independence.

2.5.1. iii ICCPR

Recognition before the law and freedom from discrimination are closely linked to independent living. Article 7 of ICCPR prohibits cruel, inhuman and degrading treatment which persons residing within institutions in the past have been and continue to be exposed to. Article 12 asserts the right to choose one’s own residence\(^{248}\). Article 17 refers directly to interference with the home and privacy. Privacy of persons with intellectual disabilities living in institutional settings is often overlooked as staff and resources cope with demands and the right to independent living can can address this issue.

2.5.1.iv UNCRC

Article 23 of the UNCRC references children with disabilities specifically\(^{249}\). It recognizes that children with disabilities have an equal right to dignity, self-reliance and participation in the community. It also highlights the need for a wide variety of assistance to achieve the personal, social and professional development of the child. The existence of adequate supports during childhood will increase the capacity of the individual to live independently and participate in their community in the future.

2.5.1.v UNCAT

The Committee against Torture has observed that community based treatment and services should be pursued instead of places of detention where a good standard of care can be achieved\(^{250}\). Although these comments were made in the context of the criminal justice system, they can be interpreted to also apply to institutions beyond the prison system where persons with disabilities reside.

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\(^{247}\) Discussed below at Section 2.5.2.


\(^{250}\) Office of the High Commissioner for Human Rights, Convention against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CAT.aspx> accessed 2 November 2017.
2.5.1. vi International disability specific instruments

The Declaration on the Rights of Mentally Retarded Persons 1971\(^{251}\), the Declaration on the Rights of Disabled Persons 1975\(^{252}\), the World Programme of Action Concerning Disabled Persons 1982\(^{253}\), the Tallinn Guidelines for Action on Human Resources Development in the Field of Disability 1990\(^{254}\) and the Standard Rules on the Equalization of Opportunities for Persons with Disabilities\(^{255}\) all reassert the rights articulated in the United Nations Conventions discussed. The equality of persons with disabilities is repeated throughout these Declarations and Guidelines. The right to health care, adequate standards of living, freedom from abuse and exploitation, rehabilitation, access to technology and personal assistance feature across these instruments also which support the realization of independent living for persons with intellectual disabilities. However, none of these instruments protect independent living to the standards afforded through Article 19 of UNCRPD. Having already examined the social movement and the need for the rights of persons with disabilities to be enshrined in international human rights law, this chapter will now discuss the negotiation process of Article 19.

2.5.2 Negotiations of Article 19

The right to choose one’s own place of residence and to the supports required in order to effect this choice first made an appearance in the UNCRPD negotiations under ‘Right to live in and be part of the community’ as Article 17 in the initial first draft text of the Convention\(^{256}\). This was presented by the Chair of the Ad Hoc Committee to the Working

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Group on the Convention and the language used provided solid foundations for the discourse which would take place over the course of the negotiations.  

‘Persons with disabilities have the equal right to choose their own living arrangements, which may include establishing their own household, or living with their families, and to the necessary financial and other support in order to effect this choice. This right includes the right not to reside in an institutional facility.

States Parties recognize the right of all persons with disability to live in and be a part of the community, and shall take all necessary measures to ensure that:

no person with disability is institutionalised;

persons with disabilities have access to a range of in-home, residential, and other community support services, necessary to effectively support community living; and

general community services are available and responsive to the needs of persons with disabilities living in the community.’

When negotiations on the content of each provision within UNCRPD began in third session of the Ad Hoc Committee in May 2004, the issue of independent living was included under Draft Article 15. Draft Article 15 was titled ‘living independently and being included in the community’ and remained included under Draft Article 15 in the fourth session. It continued to feature as Draft Article 15 through to the seventh session in January 2006. While the third session featured the widest variety of comments from delegations, this became narrower during the later sessions as more states reached a consensus on the obligations, wording and interpretations to be used in the text of the Convention.

During the sessions, issues arose which were common to the concerns of many states. The key recurring issues for what became Article 19 were the role of families/carers, the role of the state, and institutionalisation and community participation. These are discussed separately below.

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257 _Ibid_

2.5.2.i The role of families/carers

During the third session\textsuperscript{259} Thailand advocated for as broad a definition of independent living to be used as possible. Mexico further asserted that the inclusion of family residences as places for independent living was very important and as such families should be afforded the necessary supports and assistance. Morocco and Botswana supported this approach in their submissions. This was not without opposition however, as New Zealand proposed that benefits would flow naturally to families and carers when independent living policies were implemented. Therefore, there would be no need to identify families and carers as recipients of rights protection in this Article. The World Union for Programme Judaism asserted that access to information and supports for family and community based services was crucial to independent living initiatives. The importance of growing up in a family situation for children with disabilities was highlighted by People with Disability Australia and the International Disability Caucus\textsuperscript{260}.

In the fourth session, the acknowledgement of the role of families in supporting persons with disabilities to participate in communities was highlighted by Eritrea, while Mexico signalled that Draft Article 15 should be a mechanism for inclusion within families\textsuperscript{261}. Kenya recognized the need for independence in decision making for persons with disabilities who may reside with their families. This recognises that pressure may be exerted on adults with disabilities residing with their families when making decisions about their lives. The breadth of concerns and priorities for stakeholders demonstrates the complexities involved in balancing the role of families with respecting the rights of children and adults with disabilities.

2.5.2.ii Role of the state

The separation of civil-political and socio-economic rights featured heavily in discussions surrounding the role of the state in the provision of independent living models. Japan argued during the third session that socio-economic rights should be progressively realised with Sierra Leone and Argentina urging caution before imposing further demands on state resources in their submissions. This could be explained in by the economic climate of these countries. South Africa advocated for the use of the term ‘integrate’ instead of ‘include’ in

\textsuperscript{259} Ibid
\textsuperscript{261} Ibid
the context of independent living in order to ensure any persons with disabilities would be perceived as integral, rather than additional to communities. The fourth session, during August 2004, featured many reservations about the practicality of the then Article 15 with China voicing doubt. This is not surprising considering the state’s large population and the resource intensive nature of such an exercise. The fifth session saw Yemen asserting that civil and political rights were covered in other articles of the Convention and were not needed in respect of independent living. Equality and exercise of choice featured across states recommendations for adjustments to the wording throughout this session\textsuperscript{262}. Costa Rica and Russia noted the potential for the sub paragraph (c) of then Article 15 to be subject to progressive realisation due to the limits on available resources of some states, whereas the other sub paragraphs are to be immediately realised. This was also addressed during the sixth session in which Mexico suggested that as progressive realization is explained at the outset of the Convention it is unnecessary to include it in the text of individual provisions.

2.5.2.iii Institutionalisation and community participation

During the third session of the negotiation process Ireland was supported by India in its suggestion that it would be most appropriate to insert a reference to institutionalisation in this provision rather than in other articles\textsuperscript{263}. The element of choice featured in Canada’s submission to the provision of community based services and this was supported by Russia.\textsuperscript{264} Identifying women and children as requiring distinct reference within Article 15 was discussed by multiple states with the prevailing view that UNCRPD promoted unity among persons with disabilities and that sub-categorisations within Article 15 was not useful\textsuperscript{265}.

Including a provision within Draft Article 15 for the removal of institutions as residential options for persons with disabilities was supported by the NGO Persons with Disabilities Australia who argued that this obligation should also be extended to private actors as well as

\textsuperscript{262} The Coordinator of the negotiations noted the contributions which had the theme of freedom of choice. Further Jordan, Israel, Republic of Korea, Thailand, Canada, Norway and Yemen referenced the importance of equality and choice over the place of residence for persons with disabilities. Daily summary of discussion at the fifth session, 3 February 2005. \textltt{http://www.un.org/esa/socdev/enable/rights/ahc5sum3feb.htm} accessed 12 March 2018.


\textsuperscript{264} \textit{Ibid}

\textsuperscript{265} \textit{Ibid}
The National Human Rights Institutions were represented as one contributor and called for the clarification of independent living principles with Korean International Disability Convention stating that there must be vigilance to insure that independent living does not become part of a service model\textsuperscript{267}.

During the fourth session Eritrea suggested that within providing choice in provision of services, cultural practices should be respected\textsuperscript{268}. Mali suggested that considering that community participation requires interdependence among many people and services that the use of the word ‘independent’ would be an error. Canada warned that terms which could be medically interpreted should be avoided while Thailand considered ‘lifestyle’ and ‘self-determination’ as preferred terms to ‘autonomy’. Submissions from NGOs highlighted the dangers of institutionalisation again, with Bizchut, the Israel Human Rights Centre for Persons with Disabilities, explaining that while institutionalisation may not be compulsory in some states, the lack of suitable alternatives results in it becoming a default mechanism for persons with disabilities and their families.

Reference was also made to the Independent Living Movement in the fourth session, but not positively. Thailand initially suggested ensuring that independent living aspired to by the text of the Convention did not necessitate correlation with the ILM but rather independent living should be understood as a lifestyle. This was supported by Costa Rica, South Africa and Kenya. Kenya reasoned that the Independent Living Movement has not recognized or experienced in all jurisdictions\textsuperscript{269}.

The fifth session’s\textsuperscript{270} discussion of independent living took place during February 2005 and the wording and interpretation of the terms ‘living independently’ as connected to the Independent Living Movement featured heavily in this session. ‘Living independently’ was considered in the general sense of the words as endorsing self determination\textsuperscript{271}. The issue of separating independent living as a movement from the context of the Convention was carried

\begin{footnotesize}
\begin{itemize}
\item \textsuperscript{266} Ibid
\item \textsuperscript{267} Ibid
\item \textsuperscript{271} All countries agreed that the phrase ‘independent living’ or ‘living independently’ were acceptable once the ethos of non-institutionalisation and community participation were incorporated. Ibid
\end{itemize}
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on from the fourth session but inclusion and participation in community remained paramount to participating states.

The contributions by NGOs at the sixth session brought the issue of legal capacity recognition to the fore in discussions about independent living, emphasizing the centrality of legal capacity to ensure that personal choices made by persons with disabilities regarding their accommodation and resources will be adhered to\textsuperscript{272}. Australia and New Zealand favoured deleting any reference to ‘institutions’ within the text of the Article but some civil society groups such as PWD Australia and the IDC indicated that the prohibition on institutionalisation should be made clear in the text\textsuperscript{273}. The progressive realization of independent living was agreed at the sixth session but it was decided that this did not need to be explicitly referenced in the text of Draft Article 15 as it would be dealt with at the outset of the Convention.

At the 7\textsuperscript{th} session independent living was discussed under Draft Article 19 in January 2006\textsuperscript{274}. Kenya proposed the removal of any language which may facilitate persons with disabilities being removed from their communities in order to avail of assistive services. Throughout the seventh session, the issue of community versus society prevailed, Costa Rica, Venezuela and El Salvador were in favour of using the term ‘society’ but the consensus was to use the term ‘community’ which better reflects the diversity of how people live within society. The importance of home supports to enable independent living also featured prominently in the discussions. Costa Rica re-iterated that independent living does not equate to exclusion from society in any way. Similarly China, Serbia and Montenegro indicated that ‘living independently’ could give rise to persons with disabilities being de-institutionalised without the appropriate supports to engage with their communities on an equal basis with others. This would result in isolation and exclusion from communities which violates the envisioned right to independent living. The final agreed upon text reads as follows:

\textbf{Article 19: Living independently and being included in the community.}

‘States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and


\textsuperscript{273} \textit{Ibid}

appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

a) Persons with disabilities have the opportunity to choose their place of residence and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;

b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;

c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.’

From the negotiations of Article 19 it was clear that States, civil societies and NHRIs were very aware of the historic rights abuses connected to institutionalisation and exclusion from society which persons with disabilities have experienced. There was recognition of the varied forms which independent living can take across jurisdictions, the actors and supports required in realizing it. The non-specification of financial support within the text of Article 19 changed from the original draft but the most significant change from the draft version to the final adopted Article 19 is the deletion of the term institutionalisation. This recognizes that being denied the exercise of choice and control over where and with whom to live can arise in a variety of circumstances, not just through institutionalisation. The fifth session of negotiation referenced the fact that deprivation of liberty and institutionalisation are prohibited in other articles and therefore should not be included in the then Article 15. The EU suggested the wording that persons with disabilities should not be obliged to reside in an institution or any living arrangement. The issue of ‘forced institutionalisation’ is referred to by Serbia and Montenegro and Costa Rica. This could suggest that persons with disabilities could exercise choice to live in an institution. However, Jordan highlighted the fact that institutions were negative experiences which the general population did not have to experience. The reference to the right to community living adequately denotes the non-compliance of institutions as places of residence for persons with disabilities and that a process of moving persons with disabilities to the community from institutions will be a

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276 Ibid
277 Ibid
requirement for States going forward. The literature available covers Article 19 in a very broad sense from theoretical to practical application. Three themes emerged from the literature and I have divided the next section accordingly. These themes are interpreting the scope of Article 19, assessment of compliance with Article 19 and implementation of independent living. These themes also contribute to answering the main research questions discussed in Chapter 1. Having established the ethos behind the UNCRPD and Article 19 this chapter will now discuss the literature on how Article 19 has been implemented.

2.5.3 Interpreting the scope of Article 19

Perhaps the most comprehensive legal discussion of Article 19 comes from the Commissioner for Human Rights of the Council of Europe. The Commissioner considers the main elements of Article 19 to be choice, individualized support and accessibility of existing public services. The importance of Article 19 as a platform for the other rights enshrined in the UNCRPD is highlighted. In the discussion of choice as an element of independent living, the Commissioner condemns institutions as completely contrary to the rights of persons with disabilities and points out that as communities become more accessible the demand for individualized support services will decrease, reducing the cost to states. Until such a scenario is achieved however, individualized supports must play a role in establishing a minimum standard of living and providing opportunities to partake in normal life activities. As evident from the discussion on the negotiation process, it was understood that institutions did not merely constitute a large residential facility and the states demanded recognition of the concept of institutionalisation as restricting the exercise of choice and control rather than the physical settings. The Commissioner argues that the concept of progressive realization is not detrimental to progress in this area because states are required to demonstrate their efforts to maximize resources. People with disabilities need to be

280 Ibid at p. 5.
281 Ibid, pp5-6.
282 Ibid at p. 16.
283 Discussed at Section 2.5.2.iii.
informed of their rights, the services available, the choices of services, to be in a position to physically enter their communities, avail of basic services, such as transportation and to not be discriminated against in their pursuit of everyday activities.  

2.5.3.1 European Union Agency for Fundamental Rights

The European Union Agency for Fundamental Rights also provides detailed analysis of the application of independent living and the impact it has on persons with disabilities in various European states. The transition toward independent living is lauded as liberation for persons with disabilities from the seclusion and segregation which were the only options previously provided by states and service providers. The background discussion on the interaction of Article 19 with other provisions in the UNCRPD suggests the cyclical nature of realization of disability rights – by facilitating transitions to independent living, persons with disabilities have increased access to services, information and choice which was otherwise out of their reach. Better informed decisions will lead to increased participation in the community which will benefit society as a whole and increased demands will be made to further support and resource independent living and accessible societies. This report considers Article 19 as the culmination of all the rights protected within the Convention.

The FRA report indicates that there has not been one uniform response to Article 19 among Member States. Policies ranging from dedicated de-institutionalisation strategies, broad disability policies and mere commitments to cease admissions to existing institutions feature with varying degrees of successful implementation. The report is cognizant of domestic governance structures of states impacting on the delivery of independent living. States with devolved administrations usually implement independent living at the local level whereas nationally united states deliver independent living through national bodies. While the national bodies do have services based locally the mandate and method of delivery is uniform nationally. Devolved administrations have the authority to determine their own resource allocation and method of delivery. The devolved administrations are applicable to NI and BiH in this thesis. The FRA report highlights the problems that can arise with coordination between state ministries. Efforts must be made to ensure that decision-making and resource allocation roles are clearly designated within these structures. The prohibition by the EU on

285 Ibid at p. 21.
287 Ibid at p. 9.
the use of funds to Members States for investment in institutions is a positive initiative recognizing the harm association with on-going institutionalisation and the need for investment in community living.

The FRA has also established indicators to monitor compliance with Article 19. These are intended for use by Governments, civil society and disabled persons organisations and national human rights institutions. The indicators examine three elements of national compliance. Each of these elements of compliance have been further researched and a separate report on each have been published in 2017. The first examines what national legislation and policies to achieve independent living. Five opinions advised states to adopt deinstitutionalisation strategies which contained specific targets with independent monitoring mechanisms and with coordination across state regions and state sectoral authorities. These include authorities responsible for health, housing, employment and social services. The second report analyses budgetary allocations and resource commitments for independent living. Seven opinions were devised. These include the cessation of funds for institutions, the use of data collected by the state, the role of NHRI and CSOs in evaluation of state compliance and training for European Commission officers and staff of national authorities responsible for Structural Funds. The final report relates to the outcomes of the actions from the first two reports and to what degree it translates to the actual enjoyment of Article 19. Statistical data based on responses by persons with disabilities to their satisfaction with their lives and de-institutionalisation. The emerging recommendations were that states should provide a range of community based accommodation options and personalised support services, evidence based deinstitutionalisation strategies should be utilised, anti-discrimination laws should be enacted and reiterated the importance of monitoring progress.


Ibid at p. 7-8.

European Union Agency for Fundamental Rights, From Institutions to Community Living, Part II: funding and budgeting, 2017.

Ibid at p. 7-8.

and collection of data\textsuperscript{294}. Although the monitoring indicators were devised first, they should be considered as complimentary to the Europe-wide research.

2.5.3.ii Thematic report by the Office of High Commissioner of Human Rights

Resolution 25/20\textsuperscript{295} by the Human Rights Council in 2014 designated Article 19 UNCRPD as the theme for the annual report published by the OHCHR\textsuperscript{296}. The production of this report involves stakeholders from all Member States willing to be involved through accepting submissions and requesting detailed information at state level\textsuperscript{297}. It provides an overview of Article 19-compliant initiatives from a range of countries, whereas Concluding Observations of the UNCRPD Committee only focus on one state at a time. The reliance on individual provisions within UNCRPD on each other for full enjoyment of the right to independent living is highlighted in the report. The report dispels presumptions of incapability to live independently for some persons with disabilities and that society must change the protective attitude towards persons with disabilities. While the report focuses on persons with disabilities broadly, there is recognition of the increased risk to persons with intellectual disabilities for denial of legal capacity and substitute decision making which jeopardises their right to live independently\textsuperscript{298}. Among the most important issues to facilitate Article 19(a) compliance is the requirement to respect legal capacity (Article 12) and therefore allow the exercise of choice over a place of residence\textsuperscript{299}. Appropriate alternatives to institutionalisation for children include accommodation with family, extended family or a foster-care system but the report notes that significant efforts should be made to avoid institutionalisation when transitioning to adulthood\textsuperscript{300}. Initiatives in Finland and Croatia for deinstitutionalisation encompassing individualized supports and equipping individuals with independent living skills are highlighted\textsuperscript{301}. The importance of ensuring fully resourced appropriate alternatives to institutionalisation before implementing independent living programmes is very important to ensure no rights violations occur. The report suggests there will be initial double costs as

\begin{itemize}
  \item \textsuperscript{294} Ibid at p. 9-10.
  \item \textsuperscript{296} Ibid paras 20-25.
  \item \textsuperscript{297} Office of the High Commissioner of Human Rights, Disability, ‘Themetic study on the right of persons with disabilities to live independently and to be included in the community’, <http://www.ohchr.org/EN/Issues/Disability/Pages/LiveIndependently.aspx>, accessed 23 October 2017.
  \item \textsuperscript{298} Ibid para 19.
  \item \textsuperscript{299} Ibid paras 17-19.
  \item \textsuperscript{300} Ibid para 28.
  \item \textsuperscript{301} Ibid para 26.
\end{itemize}
institutions must continue alongside community living until all affected persons have successfully transitioned to the community302.

The diversity of supports required and potential suppliers of these supports are recognized by the OHCHR but the emphasis on removing the ‘care’ element of these services is paramount in order for supports to be compliant with Article 19 (b)303. In home supports must be organized around the preferences of the individuals while day care centres that are segregated from the community can risk further isolation for persons with intellectual disabilities304. The particular benefit of personal assistance for persons with intellectual disabilities is noted305. Informal social supports should be capitalized upon also but the gendered nature of support giving should be mediated as this can lead to poverty within families who are not available to engage in the workforce. Similarly where the only supports available are informal women with disabilities are at increased risk of segregation and violence306.

Persons with disabilities and their representative organisations are mandated to be involved in the implementation of Article 19 at a national level307. The report warns against independent living being exclusively within the remit of ministries responsible for health but acknowledges the interaction required for national ministries to deliver effective independent living. These include ministries for social welfare, justice and health308. Overall the report recommends states embrace a rights-based approach with fully resourced programmes for community living which are devised in consultation with persons with disabilities and which are reflective to the diverse needs of the individuals they serve.

Looking to the future, the expertise of the Committee on the Rights of Persons with Disability, the monitoring body of the UNCRPD, will be central to the implementation and evaluation of Article 19309.

2.5.3.iii State examination by the Committee on the Rights of Persons with Disabilities

Sixty-nine states have had Concluding Observations issued by the Committee on the Rights of Persons with Disabilities310. This involves state reporting, input from non-government and

302 Ibid para 27.
303 Ibid para 29.
304 Ibid paras 30-31.
305 Ibid para 34.
306 Ibid paras 35 – 36.
307 Ibid para 51.
308 Ibid paras 52- 56.
disabled persons organisations and the receipt of concluding observations from the committee in an international forum. The observations relating to Article 19 are largely repetitive across states and indicate the common nature of work to be undertaken internationally in order to fulfill UNCRPD obligations. The lack of resources and choice of place of residence and growing numbers of persons with disabilities being accepted and catered for in institutions in recent years was highly criticized, with China\textsuperscript{311} being particularly at fault for the continuation of unacceptable services such as leprosy colonies. While Hungary\textsuperscript{312} did present a plan to replace institutions with community based services the thirty year time frame in which to achieve this was deemed excessive. The progress made by Austria\textsuperscript{313} in investment in personal assistance programmes was commended but it was noted that these programmes did not adequately extend to persons with intellectual disabilities. Australia\textsuperscript{314} was warned to ensure that new disability services do not replicate old institutional settings and increased resource allocation to community based initiatives was suggested. This was reinforced by European Commissioner Nils Muznieks who warned that there is a risk of continued institutionalisation when individuals are merely moved their location instead of full independent living being pursued\textsuperscript{315}.

As discussed earlier, there are elements of socio-economic rights in Article 19. The progressive realization in Moldova\textsuperscript{316} and Armenia\textsuperscript{317} was deemed excessively slow however. Jordan’s examination suggested that persons with disabilities regarding the independent

\textsuperscript{310} As of 24 March 2018. A further seven have been examined in March 2018 but Concluding Observations have not been published. A list of states whose concluding observations are published are available at: http://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=22789&LangID=E accessed 25 March 2018.
\textsuperscript{311} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of China, adopted by the Committee at its eighth session (17–28 September 2012) Distributed 15 October 2012 at p. 5.
\textsuperscript{312} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial periodic report of Hungary, adopted by the Committee at its eighth session (17 28 September 2012), Distributed 22 October 2012 at p. 5.
\textsuperscript{313} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Austria, adopted by the Committee at its tenth session (2–13 September 2013), Distributed 30 September 2013, at p. 6.
\textsuperscript{314} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Australia, adopted by the Committee at its tenth session (2-13 September 2013) at para 41.
\textsuperscript{316} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the Republic of Moldova, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) at para 36.
\textsuperscript{317} Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of Armenia, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) at para 31-32.
living initiatives available to them\textsuperscript{318} while the experience in Iran\textsuperscript{319}, Ethiopia\textsuperscript{320}, Bolivia\textsuperscript{321}, Colombia\textsuperscript{322} and Honduras\textsuperscript{323} is of an absence of community supports. The progress at regional levels in Canada\textsuperscript{324} was welcomed but the discrimination by persons with disabilities from First Nation communities was noted. Worryingly institutionalisation continues in Cyprus\textsuperscript{325}, Bosnia\textsuperscript{326}, Guatemala\textsuperscript{327}, Serbia\textsuperscript{328}, Slovakia\textsuperscript{329}, Uganda\textsuperscript{330} and Thailand\textsuperscript{331}. The gendered nature of supporting persons with disabilities was criticized in Italy\textsuperscript{332}. Cultural, social and environmental factors were among the barriers to Article 19 adherence in UAE\textsuperscript{333}. The lack of regulation of personal assistance in Portugal was criticized. The inadequacy of community supports which exposes persons with disabilities to poverty if they do not enter institutions in Chile was noted while discrimination on the lines of gender, age and type of disability was experienced in Lithuania. There is considerable repetition with issues spanning regions and development of states. The need to provide adequately resourced community living until a full transition process has been successfully achieved was noted in the

\textsuperscript{318} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Jordan*, Adopted by the Committee at its seventeenth session (20 March-12 April 2017 at para 37-38.

\textsuperscript{319} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Iran*, Adopted by the Committee at its seventeenth session (20 March to 12 April 2017) at para 40-41.

\textsuperscript{320} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Ethiopia*, Adopted by the Committee at its sixteenth session (15 August-2 September 2016) at para 33-34.

\textsuperscript{321} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Plurinational State of Bolivia*, Adopted by the Committee at its sixteenth session (15 August-2 September 2016) at para 49-50.

\textsuperscript{322} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Colombia*, Adopted by the Committee at its sixteenth session (15 August-2 September 2016) at para 48-49.

\textsuperscript{323} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Honduras*, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) at para 45-46.

\textsuperscript{324} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Canada*, Adopted by the Committee at its seventeenth session (20 March-12 April 2017 at paras 37-38.

\textsuperscript{325} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Cyprus*, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) at paras 43-44.

\textsuperscript{326} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Bosnia Herzegovina*, Adopted by the Committee at its seventeenth session (20 March-12 April 2017 at paras 34-35.

\textsuperscript{327} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Guatemala*, Adopted by the Committee at its sixteenth session (15 August-2 September 2016 at para 53-54.

\textsuperscript{328} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of Serbia*, Adopted by the Committee at its fifteenth session (29 March-21 April 2016) at paras 39-40.

\textsuperscript{329} Committee on the Rights of Persons with Disabilities *Concluding observations on the initial report of Slovakia*, Adopted by the Committee at its fifteenth session (29 March-21 April 2016 at paras 55-58.

\textsuperscript{330} Committee on the Rights of Persons with Disabilities *Concluding observations on the initial report of Uganda*, Adopted by the Committee at its fifteenth session (29 March-21 April 2016) at para 38-39.

\textsuperscript{331} Committee on the Rights of Persons with Disabilities *Concluding observations on the initial report of Thailand*, Adopted by the Committee at its fifteenth session (29 March-21 April 2016) at paras 39-40.

\textsuperscript{332} Committee on the Rights of Persons with Disabilities *Concluding observations on the initial report of Italy*, Adopted by the Committee at its 16th Session (15 August-2 September 2016) at paras 47-48.

\textsuperscript{333} Committee on the Rights of Persons with Disabilities, *Concluding observations on the initial report of United Arab Emirates*, Adopted by the Committee at its sixteenth session (15 August-2 September 2016 at para 37-38.
Concluding Observations of Czech Republic and New Zealand. Overall the issues with which the Concluding Observations were critical are repetitive across states.

2.5.3.iv Academic literature on implementing independent living

Parker and Clements\(^{334}\) agree that a progressive realisation approach could be utilised by the Treaty Monitoring Body during a discussion of the burdensome financial implications of existing institutional, non-community based care. Hendey and Pascall’s research into the quality of life for persons in Britain in the 21\(^{st}\) century availing of independent living services is a powerful endorsement for independent living although they acknowledge that policy changes are required in order for the system to improve\(^{335}\). Adulthood was a feature of their study and there was strong connections between achieving this life status and paid employment. However due to the reliance on social welfare benefits to supplement the costs of independent living there was little prospect of individuals jeopardising this secure income to take up less profitable and secure employment. The role of families was emphasized by respondents to this research and the authors found a correlation between the level of support for and success in achieving independent living with the socio-economic backgrounds of the families involved. Interestingly there were reports of satisfaction with segregated educational settings despite legislation promoting inclusion. The focus on league tables by schools cited as reasons for reluctance by mainstream education institutions to accept students with perceived reduced abilities.

Most scholarship on Article 19 approaches independent living from a social perspective. Wehmeyer and Garner’s\(^{336}\) research states that independent living should not be dependent on achieving certain levels of intelligence and that a person with an intellectual disability must not be precluded from autonomy and self-determination. Their study involved persons with intellectual disabilities from different living situations – completely independent (has chosen where and with whom to live and is a true consumer of services and facilities accessed in the local community), congregated independent (living among other persons with disabilities but access services and facilities independently in the community) and congregated segregated


settings (residential facilities provided by institutions or organisations where services are provided within a campus and there is limited interaction with local community). Wehmeyer and Garner concluded that the provision of choice and supports was the most influential factor in the capacity of the participants to live independently.\(^\text{337}\)

Gracaman highlights the potential for expectation of support for persons with disabilities to live independently to fall disproportionately on women which results in gender discrimination.\(^\text{338}\) Cummins and Lau’s research is positive about contemporary services and their committal to service provision within the communities for persons with intellectual disabilities. However they question the value of integration to the individual. They assert that the service user must benefit from interacting with their community. They highlight that it cannot just be argued that the community benefits from having persons with disabilities participate and that this will lead to increased awareness and respecting of rights of persons with disabilities. Cummins and Lau state that the individual must glean satisfaction from community integration in order to be fully compliant with Article 19. They suggest that this approach will help to ensure that states do not pursue programmes in which physical integration is accomplished without the accompanying social integration of persons with disabilities which will encompass a broad societal shift. While they accept that no clear cut research is available to bolster a suggestion regarding the positive effects on behaviour of integrated schools, they proffer an argument that modest benefits are more obvious in living situations. They continue to explain that people belong to many different communities but the primary community, i.e. the home environment, will be most determinative.

The importance of a holistic approach to community based services and independent living is obvious in the research by Forrester-Jones et al.\(^\text{340}\). They examined the situation of persons over a decade after making the move to living in the community from long stay hospitals. Community involvement is extremely dependent on the existence of external factors such as accessible transport, services and availability of appropriately trained staff. Exposure to non-
disabled persons can increase social integration for persons with disabilities, an obvious benefit of independent living but one which requires significant state investment in public education and awareness raising. Brisenden\textsuperscript{341} argues that independent living is a right to be restored to persons with disabilities, not a luxury. This opinion is in sharp contrast to the positions of some state parties during the negotiation of Article 19 to identify independent living as a socio-economic right given the resource intensive nature of realising the right. As a socio-economic right independent living would be required to be progressively realized, subject to social and economic conditions of the state instead of immediately realised if it were a civil and political right.

Clements asserts that independent living initiatives being delivered throughout Europe are the least measure of compensation owed for historical abuses of persons with disabilities\textsuperscript{342}. He is critical of these initiatives which he deems to have been prompted by financial motivations and which do not result in real de-institutionalisation, merely a change in the physical setting of residential services\textsuperscript{343}. Clement’s concerns on the relocation of institutionalised services is reinforced by the Report of the Ad Hoc Expert Group on the Transition from Institutional to Community Based Care\textsuperscript{344}. This report defines an institution as ‘any segregated institutional setting’.\textsuperscript{345} This research was not limited to services for persons with disabilities, but included elderly persons and children who experience institutionalisation also. The Report of the Ad Hoc Expert Group addressed the concerns of states regarding costs of adhering to Article 19 were addressed\textsuperscript{346}. The authors conceded that while good quality institutional services are as economically burdensome as high quality community based services, in some instances even more so. Common Basic Principles were formulated to be utilized in the future, some of which are the inclusion of individuals affected in decision making, the prevention and elimination of institutional settings, creation of community based services, efficient use of

\begin{footnotesize}
\begin{enumerate}
\item Ibid at p. 10.
\item Ibid
\item Ibid at p. 5.
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resources, awareness raising, monitoring and the removal of funds for services which do not respect human rights as articulated in international instruments.

Bugarszki et al. have undertaken research on the practicalities of implementing Article 19 in eight European states. They report a huge gap in the level of adherence to Article 19 and describe how the EU has been criticised for its continued use of Structural Funds to build institutions rather than community based initiatives. However, in states where deinstitutionalisation has been occurring over the last few decades there is strong evidence of the benefits of individualised and person centred supports. These developed systems are not immune to the impacts of austerity measures and this can reverse progress. Parker and Clements discuss the use of Structural Funds to promote independent living in Central and Eastern European states. They acknowledge the time and resources required to make services which are accessible to persons with disabilities available. They detail the conditions for residents who experience long periods of inactivity, impersonal surroundings, lack of staff and resources for rehabilitation therapies and lack of contact with families. States availing of Structural Funds must consider their obligation to not discriminate against persons with disabilities and to act consistently with the European Charter. They suggest that while Structural Funds have been used incorrectly in the past, in the future monitoring their use will be an effective mechanism to assess the commitment of the European Union to UNCRPD realisation.

350 Ibid at p. 48.
351 Ibid at p. 48.
353 Ibid at p. 100.
354 Ibid at p. 101.
355 Ibid at p. 105.
356 Ibid at p. 112.
2.6 Conclusion

Coordination across distances has proven extremely effective in the continuation of independent living and personal assistance programmes. Pooling of finances, information, policies and technological advances was identified from early on in the Disability Movement as crucial to the success of the advocate’s efforts. Advocates in various jurisdictions had very similar experiences and the practical nature of independent living principles has lent to the successful universal application of the movement. The social and cultural upheavals in which the international movement took place was influential on its success – in America the focus on non-discrimination and rights provided a vehicle for Roberts and Heumann, among others, to ensure persons with disabilities were not excluded from such legal and social enlightenment. The emergence of the EU provided a mechanism for collaboration of activists such as Ratzka and Brisenden. The Independent Living Movement is in no way complete but lessons have been learned and are informing future actions by activists and policy makers alike.

In conclusion, from the outset, states have been appreciative of the importance of deinstitutionalisation and the provision of independent living and community based services. However, while they are aware of their obligations under Article 19 of the UNCRPD they are falling short in the fulfilment of the same. The progressive realization element of independent living may go some way in explaining why states are reluctant to invest in comprehensive independent living programmes in the current economic climate, despite strong evidence to prove that such programmes are financially beneficial. The importance of accompanying legal capacity recognition and legislation cannot be understated as the civil society organisations demonstrated during their submissions during the negotiation stages of Article 19. Without this, persons with certain types of disabilities will not have their choices on residency, services and allocation of their own resources respected and there will be no change in their lives, or that of their families and support networks. Equally by living in the community persons with disabilities will develop vital skills around decision-making.\(^{357}\) The Committee on the Rights of Persons with Disabilities will prove a powerful tool in the monitoring and evaluation of state initiatives to achieve independent living and ensure that real change is occurring on the ground.

This chapter has provided an overview of the origins of the Independent Living Movement and the standards aspired to by the founders. The standards to which I will assess the enjoyment of the right to independent living of adults with intellectual disabilities in NI and BiH have been ascertained.
Chapter 3: Northern Ireland

‘Whatever you say, say nothing’ – Seamus Heaney
3.1 Introduction

This chapter provides an overview of legislation and policies affecting the right of persons with intellectual disabilities to live independently in Northern Ireland (NI) from 1966 onward. This period of time has been one of considerable change in NI. These include a domestic ethno-nationalist conflict known as the Troubles, a peace process that is held in high esteem worldwide, EU monetary investment and ratification of the UNCRPD in 2009. Most recently and unexpectedly NI is subject to Britain exiting the EU, despite a majority vote within NI to remain. This has been followed by elections threatening the power sharing arrangement upon which the peace process is based. The chapter is divided into four broad sections – 1) Pre conflict (1960s), 2) During conflict (1970s-1990s), 3) Post conflict (1998 – 2008) and 4) Post UNCRPD ratification (2009 – present). Each section is introduced with information on the main events relating to the political landscape and the Troubles. The chapter is divided so as to clearly address the research questions set out in Chapter 1.

The first section addresses Research Question 1 – ‘How were the lives of persons with intellectual disabilities impacted by legislative and policy measures governing disability services supporting independent living in years immediately preceding the conflict?’ This section discusses legislation and policies relating to the health and social services in operation before the Troubles. This will focus on the 1960s.

The second section examines Research Question 2 – ‘How were intellectual disability services impacted by the conflict and what were the experiences of persons with intellectual disabilities during the conflict in NI?’ Due to the protracted nature of the Troubles this section will be further divided by decades – 1970s, 1980s and 1990s. The impact of the Troubles on the organisation and delivery of disability services and accounts from both interview groups – lived experience and professionals- will be incorporated into the literature.

The third section addresses Research Question 3 – ‘To what extent were the rights of persons with intellectual disabilities to live independently considered in post-conflict societies during

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360 Ibid
361 Discussed at Section 1.2.
state re-building?’ The impact of the Good Friday Agreement from 1998 onward on independent living legislation and policies and the experiences of the participants in the post conflict years will highlight the consideration of disability in NI as the peace process began.

The final section addresses Research Question 4 – ‘To what extent has Northern Ireland complied with its obligations under Article 19 UNCRPD to facilitate independent living and inclusion in the community for persons with intellectual disabilities?’ The research will consider the impact of the ratification of the UNCRPD since 2009, the associated legislation and policies and the current independent living experiences of adults with intellectual disabilities in NI.

Throughout the chapter legislation and policies relate predominantly to health and social welfare as it is under these two sectors which the majority of disability specific provisions pertaining to the delivery of services facilitating accommodation and access to the community are organised. This was reinforced through the qualitative research. Legislation and policies affecting the general population to access communities such as transport would also equally impact persons with intellectual disabilities and the qualitative research did reference these issues briefly.

As referenced in Chapter 1, participants in the professional group who participated in the qualitative element of this research highlighted the gap in information on the experience of the conflict for persons with intellectual disabilities. I have quoted the interviews as they were recorded without correcting for grammar so as not to interfere with the data.

NIP1: *[I’m really glad you’re doing this project because there is a massive gap in knowledge about the conflict in Northern Ireland and we have to struggle to try and find information.*³⁶²

NIP2: *They live in the community so they’d have very similar experiences to other people in their community but I think there has been so little research gone into what is the effect of the Troubles, of what is the effect of the conflict. So it is as if you actually lived in a different world to everyone else.*³⁶³

Along with the contributions of the professional participants in Northern Ireland asserting the novelty of this research topic, the Wave Trauma Centre research confirms the lack of

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³⁶² Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
³⁶³ Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
research on the experience of persons with disabilities\textsuperscript{364} while the Bamford Review further narrows this issue to intellectual disabilities\textsuperscript{365}. It is clear then that this research topic has been neglected and that its findings are of interest to academics and practitioners in the field of disability rights and advocacy. Central to preventing conflict in the future is understanding the impact and experiences of the past.\textsuperscript{366} This process has been undertaken for the general population but persons with intellectual disabilities have been excluded\textsuperscript{367}. As UNCRPD has been ratified in Northern Ireland such exclusion from the mainstream discourse on future disruptions to governance and potential lapses in the peace process, such as the uncertainty of the Northern Ireland Executive at Stormont and the British exit from the EU, cannot be tolerated. Northern Ireland’s peace process has been held as a standard for other international conflict resolution processes\textsuperscript{368} so collating information on the experiences of persons with intellectual disabilities can be equally useful to persons with intellectual disabilities, their families, advocates and service providers in similar situations internationally.

3.1.1 Profile of Northern Ireland

The country of Northern Ireland forms part of the United Kingdom of Great Britain (UK) along with England, Scotland and Wales. Located on the island of Ireland in Northwest Europe, Northern Ireland has a land border with the Republic of Ireland\textsuperscript{369}. The current population is approximately 1.8 million\textsuperscript{370} spread throughout six counties. The majority of the population reside in an urban area\textsuperscript{371}. NI is the most socially deprived region within the UK.


\textsuperscript{367}NIP2 and NIP4 asserted that persons with intellectual disabilities have been excluded from any discussion on the Troubles. Transcripts on file with researcher.


as educational attainment and employment rates are lower than the other UK jurisdictions\textsuperscript{372}. The Northern Ireland Executive governs the country, a devolved administration from the UK government at Westminster and is responsible for health, education, justice, enterprise, agriculture and environment. Members of the Executive are nominated by politicians at the Northern Ireland Assembly. The First Minister and Deputy First Minister are the leading roles within the Executive supported by ten Ministers\textsuperscript{373}. The Executive is responsible for the approval of legislation and national budgets to be delivered through Departments\textsuperscript{374}. There is currently political uncertainty about the administration of Northern Ireland in light of the Brexit vote\textsuperscript{375} and on-going political tensions over the Irish Language Act, among other contentious issues\textsuperscript{376}.

### 3.1.2 Context of the conflict

Economic, social and political upheaval since the 12\textsuperscript{th} century\textsuperscript{377} long before the official division of the island of Ireland in 1921\textsuperscript{378} has contributed to the political landscape of today. From 1921 until the escalation of the Troubles, NI’s governance structures were in the hands of NI as a devolved administration from the British Government\textsuperscript{379}. This had been the mode of governance even though NI had experienced sporadic incidents of violence, which Hancock describes as cyclical and connected to economic prosperity\textsuperscript{380}. The government of the newly formed jurisdiction during the 1920s reflected the Unionist majority of the population and historic Unionist institutions and prejudices from before the First World War. Lawrence critiques the complicated system of governance operating in Northern Ireland during these decades – a mixture of statutory bodies and government departments – which he

\textsuperscript{372}Ibid
\textsuperscript{374}Ibid
\textsuperscript{376}Ibid
\textsuperscript{379}‘Introduction to the Electoral System in Northern Ireland’, CAIN web service, <http://cain.ulst.ac.uk/issues/politics/election/electoralsystem.htm> At this juncture there were 73 local government authorities. Participation in elections at local government level was reserved to property owners and their spouses only, to the exclusion of up to a quarter of the potential electorate.
\textsuperscript{380}‘Northern Ireland: Troubles Brewing, CAIN web service, <http://cain.ulst.ac.uk/othelem/landon.htm>
argues were not fit for purpose towards the end of the 20th Century. The failure of the governance structures to serve the entire community in Northern Ireland was heavily linked to the alignment of Unionist dominated political agendas with judicial enforcement. The attempted peaceful assertion of civil rights for the Catholic minority and the eruption of violence are testament to the extent of the failure of the political agenda pursued at the time.

3.2 Section 1: Pre conflict (1960s)

3.2.1 Political situation pre-conflict

Based on the NI census conducted in 1966, the population of NI at this time was 1.5 million. The majority of the population resided in urban areas but there is no data available on the religious affiliations of the population at this time. Among the primary industries providing employment were agriculture, construction and textile manufacturing; although there was also evidence of significant levels of emigration in some parts of NI in the years immediately preceding 1966.

Hancock explains that prejudices and bias against the Catholic communities seeped into every aspect of life in NI. These included the police force, which started life as the Ulster Volunteer Force but evolved through the Special Constables Act (1832) into the ‘Specials’ sections of the Royal Ulster Constabulary. The need for a civil rights movement became increasingly recognised. Prominent activists in the NI political arena such as Gerry Adams and Bernadette Devlin McAliskey cited their inspiration from across the Atlantic - Martin Luther King’s Civil Rights Movement - and the rise of technology exposing Catholics in NI.

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384 Ibid
to successes in securing civil rights in other parts of the world. The NI Civil Rights Association was established in January 1967. The aims of this organisation were predominantly social justice based and its efforts focused on obtaining unbiased and transparent voting mechanisms, allocation of housing, availability of employment and the enactment of anti-discrimination legislation in government for the betterment of the lives of Catholics. It is under this banner that peaceful protests were organised and one such protest on 5th October 1968, identified by the BBC as the ignition spark for the Troubles, serves as a starting point for this research. NILE2’s support person gave an example of a similar incident which escalated violence by police forces against civilians who were unconnected to peaceful protests during this period.

NILE2 Support: Because two people they [the police] were looking for went into the house, [the police] went in and killed an innocent man in the house. That’s when the conflict started between.... People took up guns then to defend themselves, thinking, you know .... And they brought the army in then and the whole thing escalated then after Bloody Sunday.

3.2.2 Profile of Health and Social Services in Northern Ireland pre-conflict

There is very little published literature available about the implementation of disability services and the lives of persons with intellectual disabilities before the Troubles in NI. Elder notes that the ‘modern health service of Northern Ireland’ was established in 1948, in line with the National Health System in the rest of the UK. The British Medical Journal describes the NI Ministry for Health and Social Services as extremely well resourced, receiving significant investment from 1948 onward.

The 1966 census outlines the categories of accommodation delivered by the State under which persons with intellectual disabilities could have resided, although disaggregated data

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392 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
on residents with intellectual disabilities is not available\textsuperscript{395}. These include boarding houses, county welfare institutions, hospitals, nursing homes, institutions for ‘handicapped or disabled people’, voluntary homes, places of detention and establishments for ‘vagrants’,\textsuperscript{396}.

3.2.3 Pre conflict disability specific legislation

Many pieces of legislation concerning persons with disabilities were enacted during the 1960s and 1970s in the United Kingdom due to the changing nature of disability services. The earliest legislation on disability applicable during the 1960s is the Disabled Persons Employment (Northern Ireland) Act 1945. This created the option for employers of persons with disabilities to claim back costs incurred while making reasonable adjustments in the workplace\textsuperscript{397}. It also promoted vocational and rehabilitation training for persons with disabilities but preference for enrolment on such training courses could be given to former armed service staff\textsuperscript{398}.

3.3 Section 2: During conflict (1970 -1990)

3.3.1 1970s political situation

A restructuring of the health service during the 1970s was prompted by the 1969 Green Paper ‘The Administrative Structure of Health, personal and social services in Northern Ireland’ developed by the devolved government in NI. Ham, Heenan, Longley and Steel\textsuperscript{399} assert that the removal of government power from NI in 1972 positively impacted the health services that were then transferred to the remit of NI statutory bodies. Ham, Heenan, Longley and Steel’s paper cited administrative factors as the primary reason for integrating health, personal and social services, which had previously been provided by separate bodies\textsuperscript{400}. Ham et al., also consider the fact that restructuring was a result of the conflict at the time and an attempt to exert control by Westminster, in the absence of a devolved government, over public services, while removing power from discredited public representatives\textsuperscript{401}. Ham et al argue that reforms in Northern Ireland during this period were merely imitations of

\textsuperscript{396} Ibid
\textsuperscript{397} Section 15 of the Disabled Persons Employment (Northern Ireland) Act 1945.
\textsuperscript{401} Ibid

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developments within the other United Kingdom jurisdictions. From an overall population of 1,527,593, the 1971 census indicated that there were 141 residents in the category of ‘homes for the disabled’. There is also a category of ‘homes for the old and disabled’ which lists 3,374 residents. These parallel categorisations make it difficult to ascertain exact information on the population with intellectual disabilities but it does indicate that organisations providing residential services did not always operate exclusively to one section of the population.

Housing was a key issue around which civil rights discussions were organized and is also relevant to equality and non-discrimination on grounds of disability. The NI Housing Executive was established in 1971. This was a non-statutory body governed by the Housing Executive Act (NI) 1971. The legislation transferred control of social housing from local authorities to this new statutory body. Representation was unequal at local government level and according to Ham et al, the removal of power from local authorities was positive. The work of this body was especially important at a time of significant destruction through bombings of buildings, including residential properties. The use of a Selection Scheme based on need contributed to the resolution of sectarian discrimination in the housing sector. The only reference to housing for persons with disabilities in the Housing Executive report, ‘More than Bricks, 40 Years of the Housing Executive’ is under the 1976 renovation grant scheme to make accommodation more accessible. This scheme was governed by the already existing Housing Act (Northern Ireland) 1963 but accessibility requirements for persons with disabilities were not a specific feature of the legislation. Instead it focused on the prevention of overcrowding.

Ibid
Ibid at p.118.
Ibid at p. 31.
Ibid at p. 21.
‘An Act to make further provision with respect to housing (including provision for the giving of further financial assistance for the improvement of housing and provision for the abatement of overcrowding in, and the management of, houses in multiple occupation); to amend the Housing of the Working Classes Act 1885; and for purposes connected with any of those matters.’
It is clear that there were well established mainstream social services administered directly from Westminster but with significant tailoring to the NI situation at the start of the conflict. Housing was a contentious issue due to sectarian discrimination and persons with disabilities only feature briefly in the literature in relation to provision for their housing needs. The chapter will now discuss disability specific legislation and policies before and at the early stages of the conflict, identified earlier as 1966.

It was not until the more concentrated episodes of the Troubles that the Ulster Parliament was suspended in 1972. A NI Office was then established at Westminster to govern the province. Lynn notes that the efforts to determine the status of NI began almost immediately with the establishment of the NI Assembly from 1973-1974. This was advised by the ‘Northern Ireland Constitutional Proposals’, a white paper of the British Government. The fundamental argument contained therein asserted that a government in NI could no longer continue to be comprised of representatives from only one community. The arguments of the NI Civil Rights Association were being recognized, however blighted by the violence.

The Northern Ireland Act 1974 was enacted by Westminster allowing for a Constitutional Convention to determine the future of governance in NI. The Constitutional Convention took place from 1975-1976. This was dissolved after talks between the elected parties broke down despite attempts at reconciliation. These included a brief period of the NI Assembly being reinstated from 1982-1986 which failed to garner adequate support from both UK and NI representatives.

410 Kennedy, E.K., ‘Ulster is an International issue’, Foreign Policy (1973), No. 11, pp 57-71
417 Ibid
As the Troubles escalated, extreme powers for use of force were conferred on police in attempts to tackle escalating paramilitary violence. Perhaps one of the most significant events of the conflict was Bloody Sunday which took place in Derry, 30 January 1972⁴¹⁹.

No disaggregated data is available on persons with disabilities in the 1971 census. However, the census did include data on those categorized as ‘totally economically inactive’ which included persons with disabilities along with prisoners, residents of psychiatric facilities, housewives and those conducting unpaid domestic work⁴²⁰. From a population of 1,519,640 persons within the ‘totally economically inactive’ category amounted to 356,437. Collins and Pinkerton⁴²¹ identify NI as the United Kingdom’s jurisdiction with highest levels of social need. This social deprivation could arguably be connected to the conflict.

3.3.2 1970s Disability Legislation and Policy

The next significant piece of legislation was the Chronically Sick and Disabled Persons Act 1970, of which only a very small number of provisions of the extended to NI. These pertained to the composition of advisory committees on a wide range of issues, including war pensions (section 9) and committees dealing with transport issues (section 14). Positively, membership of these committees were to include persons with disabilities and those with experience of working with persons with disabilities.

The Health and Personal Social Services (Northern Ireland) Order 1972 essentially streamlined the health system and reformed the complicated structures Elder highlighted in 1953⁴²². It established the NI Health and Social Services Boards as the new vehicle for delivering health and social services. The Boards were responsible for regulating any place where medical or social services were provided. Persons with disabilities were identified as separate to patients in the Act – a positive step given the effort of the disability movement to disassociate from medical approaches to disability, but the only specific mention of persons


with disabilities relate to ‘invalid carriages’\textsuperscript{423}, with grants available to provide or maintain specially adapted vehicles.

In 1973 the Health and Social Services Boards\textsuperscript{424} were established by legislation as discussed above\textsuperscript{425}. This provided the foundation for health services until 2009 when the health service was restructured\textsuperscript{426}. The Boards in NI were based on geographical areas and comprised of Northern Board, Southern Board, Eastern Board and Western Board\textsuperscript{427}. At their establishment, each Board was required to undertake consultation with all and any stakeholders to revise the delivery of health services. While this consultation should have included persons with intellectual disabilities, there is no evidence from the literature or the qualitative research undertaken for this thesis that such consultations in fact took place. Carswell, Connolly and McAlister\textsuperscript{428} note that more money was being spent on health services in NI per head than in the other regions in the UK. The reputation of being the best-resourced health service in UK placed disproportionate pressure on the regional boards to reduce their expenditure instead of engaging in meaningful consultation with stakeholders on how to improve existing services. This issue was exacerbated further by the link between general manager remuneration and board performance\textsuperscript{429}. Smaller towns in Northern Ireland felt the brunt of the reaction to such pressures where hospitals were simply closed\textsuperscript{430}. Decisions taken regarding closures were also political\textsuperscript{431}, thus adding to the frustration among staff and service-users. Connected to this was the issue of competition between the Boards and the expectation to perform similarly despite an unequal distribution of resources.

The amended Chronically Sick and Disabled Persons 1976 Act increased the requirements for public premises such as shops and railway stations to be accessible. This Act applied to NI in its entirety. However, perhaps the most significant legislation during this period relating to the health and welfare of persons with disabilities in NI was the Chronically Sick and

\textsuperscript{423} Part V, Other Functions of the Ministry, S.30. Defined as a ‘mechanically propelled vehicle specially designed and constructed, and not merely adapted, for the use of a person suffering from some physical defect or disability and used solely by such a person’ <http://www.legislation.gov.uk/nisi/1972/1265> accessed 13 March 2018.

\textsuperscript{424} Hereinafter referred to as ‘Boards’.

\textsuperscript{425} Health and Personal Social Services (Northern Ireland) Order 1972

\textsuperscript{426} The Boards were dissolved through the Health and Social Care (Reform) Act (Northern Ireland) 2009


\textsuperscript{429} Ibid

\textsuperscript{430} Ibid

\textsuperscript{431} Ibid
Disabled Persons Act 1978. This legislation outlined the role and duty of the Department of Health and Social Services of NI to undertake research and distribute information regarding the prevalence of disability and suitable services to those who needed it. A multidisciplinary and holistic approach to services is provided for under Section 2 of the Act and explicit reference is made to recreational, educational, transport, personal assistance, communications and holiday facilitation. This legislation ensured that the legal provisions for persons with disabilities in Northern Ireland were finally on a par with the rest of the UK.

Disability Action highlight the positive impact of the report of the Silver Jubilee Committee on Improving Access to the Built Environment in NI in 1979 which suggested that each local authority designate a staff member, preferably within the Planning section, to serve as an officer for issues related to accessibility for persons with disabilities. However, Imrie and Wells are critical of the implementation of many of the Silver Jubilee report’s recommendations. For example, they highlight that the requirement to ensure an Access Officer is present in local authorities to attempt to compel developers adhere to accessibility requirements had very low take up. Imrie reiterates the lack of progress on the ground achieved by the Silver Jubilee report by highlighting that even a conclusion that the inaccessibility of physical environments was ‘tantamount to an infringement of the civil liberties of people with disabilities’ did not prompt any significant improvements for those most adversely affected. These initiatives are reflective of the Independent Living Movement’s initial focus on persons with physical disabilities (in both Northern Ireland and globally) but they also have the potential to improve the experience of persons for whom both physical and intellectual disabilities are present.

The childhoods of the participants with lived experience in the qualitative research spanned the 1960s, 1970s and 1980s and reflect their experiences and knowledge of the political conflict while growing up and how this impacted on the potential for independent living. To reflect the chronology of the life course alongside the contributions from the professional participants, references to childhood are discussed here. The themes that emerged in relation

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432 Section 10 of the Chronically Sick and Disabled Persons Act Northern Ireland 1978.
435 Ibid
to this time-period for participants were their living arrangements, education and involvement in the conflict. These will be discussed separately in the following sub-section.

3.3.3 Living Arrangements

Table 6. Description of living arrangements of participants NI.

<table>
<thead>
<tr>
<th>Place of Residence</th>
<th>Immediate Family</th>
<th>Extended Family</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>1</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
</tbody>
</table>

The 1966 census indicated that only 138 persons were resident in ‘homes or institutions for handicapped or disabled persons’\(^437\). Only two institutions are listed as being counted in the category - one in Belfast and the other in Co. Down. However there are also populations resident in hospitals and care facilities. The majority of participants with disabilities in this research spent their childhoods in family homes. Only one participant had been placed in a religious institution in a neighbouring jurisdiction as a baby and this institutionalisation continued throughout adulthood. With this participant’s permission, her support person outlined briefly the typical situation of religiously provided institutions during the participant’s youth.

NILE1: *We all moved out, weren’t allowed to stay there*\(^438\).

Supporter: *I think from birth up to a year you had to stay in (named place) that was more of a nursing, type of an ante-natal ward. You know after the baby is born. And then that was it, a year old took them out of there. Put them elsewhere.*

NILE1: *I was there, went to school there when I was 3. Then went to (neighbouring jurisdiction) when 4 years of age and was there ‘til I was 15.*


\(^{438}\) Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
Ok, from [age] four to fifteen. And did you have any choice over that? Did you know that you were going to go to (neighbouring jurisdiction)?

NILE1: No, I didn't know, I was just sent. I had no choice. Just had to go, and that was that. But they didn't allow me to stay in (neighbouring jurisdiction) because I wasn't from (neighbouring jurisdiction). Had to go back to the North again.

Do you know why? Was it just because there wasn't a service?

NILE1: Aye, because they didn't allow me, you know.

It is clear that even as an older child there was no involvement in decision-making or explanation as to how and why such important decisions were being made. This institution was run by a religious organisation so the participant experienced full religious segregation during her childhood. Other participants spent their childhoods within family homes and this ranged across rural and urban settings. Only one participant had one other sibling, the others had large families and nieces and nephews were features of their life stories and as support networks in later years.

Due to parental separation, NILE2 returned to NI from a neighbouring jurisdiction as a child during the Troubles and resided with his maternal grandmother for a time before settling with his immediate family. NILE3, NILE4 and NILE5 all recounted living with their immediate family and spoke positively about siblings as part of their childhoods.

3.3.4 Education

Table 7. Educational format NI.

<table>
<thead>
<tr>
<th>Education</th>
<th>Gender</th>
<th>Total disability segregation</th>
<th>Mixed mainstream and disability segregation</th>
<th>Religious and disability segregation</th>
<th>Gender segregation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
</tbody>
</table>

All participants in NI received segregated education for persons with intellectual disabilities at some stage in their childhood. The education provided varied based on the impact of the disability on learning pace and the effectiveness of educators and professionals to identify an
intellectual disability. Two participants received special education throughout their childhood, two participants joined special schools at later stages and one could not recall the education she received, although segregated education is strongly suspected due to the nature of her disability – Down syndrome – and her recollection of being required to travel a significant distance to go to school. Questions were also asked about the religious ethos of their schools – not specifically identifying their own religion but to ascertain whether special education, where provided, was divided along religious lines.

NILE1: Aye, I couldn't pick up with the rest of the children in (local institution) and that's why I had to go to (neighbouring jurisdiction). A backwards school.

Supporter: For people with learning disabilities.

And did people use that word ‘backwards school’?

Supporter: Oh aye, back then they wouldn’t have used learning disability.

NILE1: Very slow picking up you see. I learned then when I was there. I knew everything when I left it.

So the [staff] knew how to do school for people with learning disabilities?

NILE1: Aye, it was over 200 children in the home.

And what did you do? Was there an inter-cert or Junior Cert? Did you get a qualification from your school?

NILE1: Yeah, I learned the time and all. I didn't know [how to tell the time] when I was in (institution).

NILE1’s account of being able to tell the time, rather than reference to any certification or vocational training does not reflect well on the standard of education provided within a religious and disability segregated institution. NILE1’s experience of education seemed to be the most limited of all the participants. NILE2 had negative experiences being moved from mainstream education to a ‘special school’ in the area. While NILE1 was totally segregated in terms of religion and disability, NILE2 experienced segregation due to disability but not religious segregation. He recalled how this segregation prompted bullying from both within and outside the school, highlighting the awareness that peers and the community had at the

439 Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
time of the difference between the students in the schools in the community and the understanding of one group of students as inferior to the others. However, NILE2 did take pride in the fact that he exceeded expectations at school to the extent that he was moved ahead a year. He is the only participant who spoke in such detail about education and acknowledged the impact that the experience had on his later life.

NILE2: [I] was more accepted down there [in the segregated school]. Most people like me were more accepted at (special school).

Researcher: And was that school mixed boys and girls?

NILE2: It is totally mixed boys and girls and both sides of the religious divide as well. .... I didn't mind the religion but what I did mind at the time, through my own ignorance and perceptions, from a primitive mind at the time, was when I found out later on that I had a disability I didn't accept that I had a disability. I didn't want to accept it and I was called names for going to a special needs school.

Right

NILE2: But what I would say is the special school was the right school for me because there were less children in the class, 13 compared to 30 in a mainstream school. So it was the right school in the end.

NIP4 recalled instances of bullying behaviour based on perceptions of school attendance, although she doesn’t think that all incidents were disability motivated. As schools were associated with a particular area and ethnicity this behaviour was more likely based on sectarian discrimination than on disability. This demonstrates the multitude of discrimination potentially experienced by persons with intellectual disabilities.

NIP4: I knew people who were beaten up because they were wearing the wrong school uniform in the wrong area. Having a disability or not, you just got beaten up.

Sorry, so people with a disability were beaten up?

NIP4: Oh yes, you know just because you were in the wrong uniform...

Would they have known why they were beaten up?

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440 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
Well their family knew why they were beaten up, yeah.

And the people beating them up, would they have known that they had a disability?

Not necessarily.\footnote{Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.}

Transport to school was also segregated for students with disabilities. It was only after prompting from the support person, that NILE2 acknowledged this, and he was unable to recall if people on the bus with him were from different religious backgrounds – he had earlier said that the school facilitated students from both sides of the religious divide.

NILE2: Well all the people on the bus were from my school so aye.

Supporter: I think (X school) too had their own bus

NILE2: Yeah, their own bus.

Supporter: And the (X school) had their own bus. And the (Y School).\footnote{Extract from interview with NILE3, 5 April 2016, transcript on file with researcher.}

For one participant it was difficult to determine whether she had attended mainstream or special school but her account of having to travel a significant distance could indicate that she received special needs education.

NILE3: I went to X House, it was in (named city).

Supporter: So, the one in (named city) was about 40 minutes away.

NILE3: Something like that, aye [yes].

Supporter: 45 minutes on a bus. That was a long distance to go wasn't it? It was the bus for ladies, young girls.

It was just for girls this school?

NILE3: Yeah, in a house beside the school.\footnote{Extract from interview with NILE3, 7 April 2016, transcript on file with researcher.}

I attempted to clarify with her at a later point about the education she received and the impression was given that the ‘house’ referenced, the building near the primary school, was also an educational institution.
NILE3 described attending higher education ‘like ordinary people’. This could suggest a graduation from education segregated along disability lines. Speaking about the mixed religion of students the participant recalled: ‘I liked it. I liked it myself’.\textsuperscript{444}

Special education was not received at primary level for NILE4, who attended the local religiously run school. NILE4’s response of ‘No. Plain just’ when asked whether her primary school had been for persons with disabilities is indicative of a perception of special education as outside the norm\textsuperscript{445}. There was also a shift from attending a mainstream religious school to a religiously integrated special needs secondary school but she indicated that she did not receive a formal qualification. NILE4 reported that she was satisfied with attending school with people from different religious background to herself and her answer suggested to me that she did not want to pursue the topic much further. ‘Everyone got along ok. Nope, alright.’\textsuperscript{446}

NILE5 was very clear on the fact that he had attended a school for children with disabilities with children of a different religion to himself but did not recall any sectarian incidents\textsuperscript{447}. The lack of conformity of schools for children with disabilities on religious segregation was one aspect which NIP1 commented on.

NIP1: [Y]eah disability could have been one area where religious segregation we kind of pushed to the side a bit. When you think of schools in particular, special schools were generally integrated rather than segregated in the sense of Catholics’ and Protestants’ religion.\textsuperscript{448}

Overall, segregation for special education rather than religious segregation was the prevailing model in education among interview participants with disabilities and this is reinforced from the interviews with professionals. The participants seemed satisfied with the standards of education they received overall, although there were significant variations in the educational outcomes from being able to tell the time to vocational training. Contributions from the professionals on the right to education will be discussed further below in light of developments in the 1980s\textsuperscript{449}.

\textsuperscript{444} Extract from interview with NILE3, 7 April 2016, transcript on file with researcher.
\textsuperscript{445} Extract from interview with NILE4, 7 April 2016, transcript on file with researcher
\textsuperscript{446} Extract from interview with NILE4, 7 April 2016, transcript on file with researcher.
\textsuperscript{447} Extract from interview with NILE5, 12 April 2016, transcript on file with researcher.
\textsuperscript{448} Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
\textsuperscript{449} This will be discussed in relation to legislation at Section 3.3.7.
3.3.5 Leisure activities during participant’s childhoods

Leisure activities during childhood did not feature in all the interviews but were discussed to a greater extent regarding adulthood. NILE1 resided in an institution in a neighbouring jurisdiction during the years coinciding with the start of the conflict. As would be expected in a religious institution, residents were required to contribute through chores and had significant limitations on their liberty to leave the grounds. While some childhood leisure opportunities were created these were punctuated by the rigidity of institutionalisation.

NILE1: Oh I knew I couple of the children they were all around my age. Aye, we used to have good craic [fun]. We made our own fun. We used to climb up the trees for apples and jump over the hedges and up the drain pipes, hahaha.

Supporter: You were robbing orchards, huh?

NILE1: We had to make our own fun. Life was hard you know..... [I] used to cook at dinner time for the pupils that went home during the day. We used to do the cooking for them.

And was that a job?

NILE1: No, just at school time. Part of our school thing.450

NILE3’s leisure time was connected to being at home and although she indicated close proximity to the town she did not mention availing of recreational facilities there.

So then when school was over, what did you do in the evening time?

NILE3: Had a wee [short] break in the house.451

Similarly NILE4 didn’t provide any information about leisure activities in her youth, instead focusing on her routine as an adult in her family home when she had completed her education.

So right after you finished your secondary school what did you do?

NILE4: I don't know where I went. I had to stay at home.452

450 Extract from interview with NILE1, 45April 2016, transcript on file with researcher.
451 Extract from interview with NILE3, 7 April 2016, transcript on file with researcher.
452 Extract from interview with NILE4, 7 April 2016, transcript on file with researcher.
No interviewee described any disability service during the conflict outside of the educational institutions in their childhood. NILE2 made brief reference to the lack of any disability services that he could have availed of in his youth:

Researcher: [S]o when you were younger did you have any services connected to your disability outside of school?

NILE2: Not that I was aware of. If there was, I wasn't in them, I didn't know of any. There was when I was older, (named disability service) but I wasn't a part of it. For some reason, I don't know why.453

The lived experiences reflects the variety of accommodations reflected in the legislation and policies of a mixture of family support at home and institutions. Segregated special needs education was delivered in a neighbouring jurisdiction through a religious body but this was not the experience in NI. While mainstream education was delivered in a religiously segregated format, education for persons with intellectual disabilities was not segregated along religious lines.

3.3.6 1980s political context

While no specific data on persons with intellectual disabilities is available, the 1981 NI census indicated that over 4,000 people resided in homes for the elderly and the disabled, the majority of whom were female454. The category has been slightly changed from the 1966 and 1971 censes which did not include elderly persons. Politically motivated violence continued to be perpetrated by paramilitary groups on both sides, which led to deepening social divides as prisoners in the infamous H-blocks went on Hunger Strike to be recognised as special category prisoners455.

3.3.7 1980s disability legislation and policy

Meanwhile in England, Scotland and Wales the recognition of the transport and accessibility needs of persons with disabilities during construction of highways and buildings as well as provision for accessible signage was enshrined in the Disabled Persons Act 1981. This

453 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
corresponds to the positive advances in NI in the aftermath of the Silver Jubilee Committee on Access to the Built Environment, which Disability Action highlighted.\textsuperscript{456}

The Mental Health (Northern Ireland) Order 1986 established the Mental Health Commission of NI\textsuperscript{457} with an expansive remit governing services for persons with ‘mental disorders, handicap, illness and impairment’. Compulsory admission to hospital and guardianship feature heavily in the legislation. It details in depth procedures relating to patients subject to criminal proceedings (Part III), consent for treatment (Part IV), registration of private hospitals (Part VII) and management of patient property (Part VIII).

The final piece of legislation of note during this period is the Disabled Persons (Northern Ireland) Act 1989. It brings NI legislation into line with the Disabled Persons (Services, Consultation and Representation) Act, 1986 and applies to persons with physical, intellectual and mental health disabilities. This allows appointed representatives’ such as carers or guardians, rather than the person with a disability to make decisions in respect of personal and social services.\textsuperscript{458} The legislation makes increased provision for the assessment of the abilities of the carer (Section 8) and requires consultation with organisations providing services to persons with disabilities where appointment to committees of representatives with specialised knowledge of disability is required (Section 9).

The unique nature of governance in Northern Ireland, which alternated between self-governance and Direct Rule as a result of the conflict, is highlighted by NIP2 as a key reason for a relative dearth of disability legislation in NI and this explains in part why the focus is more on policy development than on disability legislation.

\textbf{NIP2: So in Northern Ireland, in part because we had direct rule rather than our own assembly we would have had policy rather than legislation.}\textsuperscript{460}

The discussion will now turn to health and disability policies in effect as the conflict escalated.

\textsuperscript{457} Mental Health (Northern Ireland) Order 1986, Part IV.
\textsuperscript{458} Section 1(6) of the Disabled Persons (Northern Ireland) Act 1989.
\textsuperscript{459} These are not disabled person’s organisations, where key roles in leadership and organisation are filled by persons with disabilities.
\textsuperscript{460} Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
Disability Action note that funding was made available in 1980 to establish the first Information Service for disabled people\textsuperscript{461} based on a recommendation of the Silver Jubilee Committee report. These positive initiatives were further bolstered by the designation of 1981 by the United Nations as the International Year of Disabled Persons \textsuperscript{462}. A development officer was appointed within Disability Action, under the auspice of this international recognition of persons with disabilities\textsuperscript{463}.

The need for diversion of care for persons with all forms of disabilities from hospitals to within communities was identified in the ‘1987-1992 Regional Strategy for Health and Personal Social Services’. The goal of this strategy was to determine the most cost and resource effective manner of highest quality service delivery\textsuperscript{464}. McKillop et al found in their independent analysis of NI hospital standards at the time that the move toward community care did render significant cost savings\textsuperscript{465}.

In 1988 ‘Community Care: Agenda for Action’, known as the Griffith’s Report, was published in the United Kingdom. While it was not specifically applicable to NI, it is indicative of the slow movement away from what had been persistent medical model of disability services that were expensive to implement, difficult to change and did not serve their target participants\textsuperscript{466}. The author placed the focus on consumer-led services\textsuperscript{467} that finally incorporated the aims of the hard fought Independent Living Movement. He suggested that local authorities should be responsible for sourcing best value for money from independent services providers\textsuperscript{468}. While legislation and policies for the delivery of services

\textsuperscript{462}As discussed in Section 2.4.2.
\textsuperscript{463}Ibid
\textsuperscript{465}Ibid at p.180, ‘For example, between 1987 and 1992 the share of secondary care in the total revenue expenditure of the Health Boards fell from 54.4 per cent to 50.6 per cent’.
\textsuperscript{466}Laming, H., ‘The Personal Social Services’ at p 42, ‘The general feeling that services were not achieving the standards expected of them either in quality or in quantity was exacerbated by a growing belief in some quarters that all social problems were the responsibility of the state and that ‘they should do something about it’. For a time the state services almost became isolated from the public who owned them and whom they served. The part which could and should be played by others was often minimised at the very time that it ought to have been accentuated and developed.’ <http://www.psi.org.uk/publications/archivelpdfs/New%20dire/ND15.pdf> accessed 5 April 2015.
\textsuperscript{467}Community Care, ‘Knock it down and start again’, October 20, 2005 in Adults, Children, Inspection and regulation, Workforce, available from:<http://www.communitycare.co.uk/2005/10/20/knock-it-down-and-start-again/>.
\textsuperscript{468}Understanding Disability Policy, Key legislation, papers and reports. <http://www.policypress.co.uk/resources/roulstone/keylegislation.asp#1980
in Northern Ireland was delayed compared to the UK, financial support for persons with intellectual disabilities to live independently in NI was on a par with that provided in the rest of the UK. These payments were predominantly covered under the remit of unemployment benefits. Burchardt outlines how the means tested Income Support benefit was replaced by Invalidity Benefit but these supports did not differentiate between those who had acquired a disability through work and those whose disabilities prevented participation in the workplace. Efforts to address poverty arising from disability were made through the introduction of the Attendance Allowance (1971) and Mobility Allowance (1975), which recognised the need for personal assistants. However, these had little impact on addressing poverty as intended.

NIP4’s account reinforced the attempts by high level health service staff to move from large scale residential institutions during the 1980s and the efforts to transition away from this style of service. However, there was no reference to service user involvement in the planning for these transitional initiatives.

NIP4: *I remember going to meetings in 1982 about the future of X hospital, at that time it had nearly a thousand patients. Meetings being held by (regional health board) who ran the hospital on what the future of the hospital should be. And how to affect the shift from hospital based services to community based service.*

Legislation relating to education for children with intellectual disabilities was highlighted by NIP2. She criticised the delay in recognition of educational rights for persons with intellectual disabilities in NI, compared with their mainland UK counterparts stating this had a negative impact.

NIP2: *[Y]our right to education was much further back [than] in England. For people in Northern Ireland, my right to education the same as everybody else only happened in 1986. So really quite recent. So before that I was seen in-educable, so my ability to make my own way either in my local community or with other communities was limited by circumstances if you like of the conflict. I think in terms of England, their sense of having a right to education*

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469 Personal correspondence by e-mail with Goretti Horgan, School of Criminology, Politics and Social Policy, October 26 2017.
471 *Ibid*
472 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
and having a rights base was probably more developed than it would have been in Northern Ireland. So that meant that I think people with learning disabilities came late to seeing themselves as rights holders.\textsuperscript{473}

NIP4 also highlights the importance of the recognition of the right to education for children with intellectual disabilities and the unconventional manner in which it came about – the threat of litigation by a family member.

NIP4: \textit{One of the things that we recognized, most of the beneficial changes has come about because of legislation. Things like 1987, the right to education, finally, only in 1987 was the right to education established.}

\textbf{Was that just in relation to people with learning disabilities or in general?}

NIP4: \textit{People with intellectual disabilities, other people had the right to education but people with disabilities were excluded. It was a mother’s threat to take the country to the European Court of Human Rights that made that change. I was at the meeting when it started.}\textsuperscript{474}

While the right to education which NIP4 is referring to was established through the Education and Libraries (NI) Order 1986\textsuperscript{475} it could have taken a year in order to become fully operational. In practice, education was provided to some degree before this, as evidenced from the accounts of the lived experience participants in this qualitative research. Professionals indicated this was a national trend which had to be strongly advocated for by families\textsuperscript{476}. However, as seen above at Section 3.2.4 the standards of education varied across the participants depending on the educational setting – mainstream, disability/special needs segregation or religious segregation.

Returning to initiatives for independent living, a UK-wide Independent Living Fund was established in 1988 which was available in NI. Murphy\textsuperscript{477} outlined the purposes of the fund

\textsuperscript{473} Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.

\textsuperscript{474} Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.


\textsuperscript{476} NIP2 and NIP4 made references to families advocating for education for their children with intellectual disabilities. Transcripts on file with researcher.

as providing resources for an individual to employ supporters/carers or to engage a care agency to provide personal services. Eligibility for the fund was linked to the individual’s social welfare payment. Until 2015 up to 46,000 people have benefitted from the fund across the UK  but it is not possible to disaggregate this figure for NI. The Independent Living Fund will be discussed further in the section on 1990s disability legislation and policy below.

3.3.8 1980s disability services

Disability services for day activities and socializing were a feature of young adulthood for participants. Interviews with the professional group indicate that day services were provided for adults with intellectual disabilities and integrated along religious lines during the Troubles. NIP4’s experience indicates the novel nature of investment in intellectual disability day services during the 1980s, which was considered important in the provision of independent living.

NIP4: So it was a brand new facility that had been built to meet the day service needs of people. And actually an important building block in deinstitutionalisation was daytime activities and support for carers.

And that was as far back as 1981?

NIP4: Yeah, from December 1981. There were 120 places.... It was the first day facility for people with profound intellectual disabilities or multiple disabilities and people with challenging behaviour. There was a special unit for those two groups of people who tended to be excluded in services completely in the community. So that was pretty revolutionary.

NIP1’s account verifies this segregation when asked about disability services from the 1980s and 1990s.

NIP1: In terms of services I’d say they generally have been quite mixed. So that is maybe positive in that sense, that disability seems to have been placed above religious divides. But there would have been an issue in other areas where a service may have been provided in an

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479 See Section 3.3.10.
480 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
area and maybe someone from a different religious background would have had to go to that service in particular.\footnote{Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.}

NIP4 had mixed opinions about the benefits arising from disability being an area which was exempt to an extent from political connotations.

NIP4: I think ..... Yes. There was a good side and bad side to that. In a way disability floated on the top of the sectarian divide and there was a very positive thing about that in that two communities were mixing and being productive and positive together. The negative side to that was they did that because they didn't think that people with intellectual disabilities had political opinions or identities. Assuming this stuff won't matter, where it did. People had the opinions of the areas they grew up in and the families they grew up in.\footnote{Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.}

As with any service delivered to the public during a conflict, significant difficulties were faced in the provision of disability services during the Troubles. While there are accounts of disruption to other services\footnote{Wharton, 'Wasted Years, Wasted Lives. Vol. 1: The British Army in Northern Ireland 1975-77, Havertown: Helion & Company, 2013, at p. 150.} in the literature, I was reliant on the qualitative research to understand how disability services were impacted.

NIP1: Issue with how services are delivered in terms of conflict itself impacted on that [people attending services] because there have been situations where local community centres, day care centres for disabled people, they haven’t been able to go to them because of the Troubles happening around them, bomb scares and so on, roads being closed off. So those things really impacted on disabled people at the time.\footnote{Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.}

NIP4 noted the setbacks that travel disruptions and violence had on independent travel for adults with intellectual disabilities using day services. Equipping people to travel independently was important to minimize the disruption that transport provided by services experienced due to the conflict. She recalled how persuasion of families was required to gain their confidence for their family member to undertake independent travel on public transport.

NIP4: So the trains weren’t running and the buses couldn’t get in. So the centre was a little bit isolated and we now had 50% of our people travelling independently and stuck because they couldn’t get in and we didn’t know where they were. But what we learned from that is

\footnote{Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.}
just how sensible people with intellectual disability are. That once they've learned to do something, they do it right and take care of each other which was the other thing. We eventually got messages from people who had walked to the nearest home. So a group that normally came from X train station, when the trains weren’t running they stood there chatting to each other and eventually decided to go to (a service-users) house in X road and they went there and phoned and said we’re here at this man’s house. We said, ‘Stay there and we’ll get somebody out to collect you’. And that was the kind of thing that happened. I remember on that Monday there was one woman still unaccounted for, accounted for most people but this one person still missing. Boy were we anxious, because you know we had fought for independent travel and had persuaded the families to trust us, persuaded the adults with intellectual disabilities to trust us. And this one woman was missing, she had limited communication skills, a practical woman who knew her way around but didn't speak very clearly. She was still missing and it was hours later and search parties [were] out and all the rest of it. Then somebody spotted her coming across the playing field behind a hospital. She had managed to re-route herself to the way she could walk in and come through a hole in the fence. Well the celebration when she arrived!  

The resilience of persons with intellectual disabilities to disruptions caused by the Troubles is also demonstrated in NILE1’s account of attending to her place of work which was organised by her disability service.

NILE1: I told them that we had to go home early, 'cos of the bomb scares. Told us all to get out. The army came in to (named workplace) and asked everybody their names.

Supporter: Oh I know all about it, they’d come in the next day. It is hard to describe. Um, the reason X wouldn't have been afraid going back was you weren’t going in to the heart of the trouble. You were going back into your own safe area, therefore you didn't feel scared. There was always a thinking of anybody working in a troubled area, if you’re going home and anything happens, knock on someone’s door and they’d let ya in. And that was always on people’s mind. When X was going home you know she said, there’s always a house to go into. People would have knocked on people’s door and they’d have brought them in out of the road of the Troubles. It was that bad. I mean in terms of, you’re from Donegal, people say in terms of the Troubles in (named city) you know they must have been bad. A lot of people you know don’t realize how bad they were. You’re going to your work in the middle of a gun battle and

485 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
you've bullets flying everywhere. And then there’s a bomb going off here. People in (named city) are very resilient, as in (other named city) but you have to go to your work. Because you couldn't live. But when you got into a certain area, the hump [stress] came off your back. You’d walk home and when you got out of (named workplace), (conflict zone) area, out of the (conflict zone) and into parts of (residential area) you no longer felt any stress because you knew you were away from the conflict. But if you’re stuck in the middle of the conflict and moving in towards the conflict there wasn’t a lot you could do about it, you were stuck in the middle of it. And that's why people always said look if you’re stuck in the middle of a bomb blast or in the middle of the Troubles, knock on a door and someone would let you in. And that was a known thing in (named city), anyone in trouble, people would let you in their house and that’s what happened. And that’s what X meant, when she said she was going back, it was the same everywhere in (named city).

NILE1: I remember a time in (named work place) the (named family), they barricaded, they wouldn't let us in the door. We had to go home again.

And did it ever happen that you did have to go into someone’s house?

NILE1: No, I just went on home.486

The self-sufficiency of adults with intellectual disabilities is clear from the above accounts as they encountered disruption to their daily lives alongside the general population. The next section considers the involvement of persons with intellectual disabilities in perpetrating violence during the Troubles.

3.3.9 Involvement of persons with intellectual disabilities in conflict

NILE2 was still a child during the early 1980s. He recounted that stone throwing at the British Army was common practice among his peers and that little to no sanctions resulted from partaking in it.

NILE2: There was a lot of stone throwing. I remember doing that myself as a child but I didn’t know why I was doing it, I just did it because my friends were doing it.

And did your friends also have learning disabilities?

NILE2: No, not the ones that lived near me. Naw.

486 Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
Did you ever get in trouble for it?

NILE2: Naw. See it was back in the early 80s, I can’t really remember.

What age would you have been then?

NILE2: Around eight or nine.487

The support person also went on to contextualise the actions of NILE2 in his youth as normal activity of the time but was concerned about danger that NILE2, along with his peers, did not seem to realise they were in.

Supporter: *X is saying that he was down, a lot of people down then, for want of a better word we’ll call them youths, they’d have known no different, people around 12 and under 12 were in the street, they seen adults throwing stones that was the next thing to do was pick up stones, whether you had a disability or not. But then with X stuck in the middle of it with a disability, he was stuck in the middle of the trouble and there was nobody saying to him, X you can’t do that. This was carte blanche where everyone was in the Troubles. And you've seen photographs of wains [children] 9,10,11 years of age in (town land) and cars going past and there’s 20/30 children just stoning it. And that happened throughout (named city), in (town land), all over the place. And that was part of what X was part of, it was more dangerous part because then the shooting started. They were shooting, I mean anybody that moved at night – shadows - they were shooting.*488

NIP2 highlighted how having a disability would have impacted on the ability of persons with intellectual disabilities to socialise with the Troubles compounding protective attitudes from family but she doubted this would be reflected in literature.

NIP2: *I suppose in terms of if you’re growing up in a conflict situation. Well first of all my parents, if I’m a person with a learning disability my parents are going to be more protective about me so they’re going to be more anxious, I’m going to have less freedom and also because of the nature or uncertainty that came with that conflict. So I didn’t know if that bus was going to travel from A to B, it could be going from A to Z to C so those uncertainties and my family’s natural desire to be protective about me meant that I was probably even more restricted in my movements, who I saw and what I did. And therefore it was probably more*

487 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
488 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
home based and more linked into my family. So it had that impact on people with a learning
disability that I think is different to the rest of the population. While there was always no go
areas, or you couldn't mix there and go there, there was still a path of freedom within a
community to move around and I don't know if that was the same for people with disabilities.
So that would mean that the contrast for, and I'd say this is at an anecdotal level, rather than
any research or evidence papers.

Later in the interview she said, [A]necdotal that perhaps people who had moderate learning
disabilities, may have been on the fringes of paramilitary activity. May have been involved
perhaps as look out people. You can imagine how attractive that might be, being part of a
gang and a group, all the excitement that's going on as part of that group so that desire to
belong and be part of something. But it did also mean that I may be more easily caught, I
may not be as good I guess at using the system, or knowing what my rights are and those kind
of things. So to me those are some of the impacts of the conflict on and I guess the very
invisibility of the population. 489

The above accounts indicate a major lacking in activities for young people with intellectual
disabilities after school. McGrelis 490 suggests that the Troubles themselves offered a sense of
solidarity or ‘bonding social capital’ for young people at the time, which is alluded to by
NIP2’s anecdotes of the attractiveness of membership of gangs.

According to the professional participants in this research, disability services were not
immune from internal sectarian incidents but these were managed carefully. The constant
attitude of suspicion that was a perceived necessity for survival in some communities affected
the culture at workplaces and resulted in a rejection of managerial authority.

NIP4: When people got angry they would hurl sectarian abuse at each other but they didn't
have a choice did they [over who they attended services with]. There were people who would
chose not to come to a particular service because of where it was located. And mostly it was
a perception of safety but also that was about identity and being accepted. 491

NIP5: [W]e had a man with us who belonged to (religion) who said he wouldn't accompany
somebody we support to attend religious services (for a different religion). That was against

489 Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
490 McGrelis, S., ‘Pushing the boundaries in Northern Ireland: Young People, Violence and Sectarianism’,
Families & Social Capital ESRC Research Group London South Bank University
491 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
his (religious) values. And we had to deal with that because that's not in keeping with our organisational values. .... We had a guy we supported who had been in a long stay hospital but sort of left that during the early 70s when a lot of very horrible things were going on. When he came back to live in the community he still found it, he wasn’t sensitive to the fact that you couldn't use sectarian language and threatening physically, he wasn't physically threatening people but he’d say things like ‘I’ll get the boys on you or get someone to get you’ 492 and obviously that makes people very anxious. I suppose it's just, you know, people would say. It's not that unusual. I've been threatened by a parent once they were going to get the IRA to shoot me in the knees’ or whatever. And I suppose because of the Troubles people here use those sorts of threats where somewhere else people would say I’ll get my mates to kick your head in or something like that. [Chuckles]. Where people say they’ll get the IRA to shoot you in the knees or whatever, it is just different. 493

All participants with lived experience had knowledge of the conflict with three being more directly affected than the others. All participants in the professional group also provided accounts of how disability services were impacted through their own personal experience or based on their general knowledge from the time.

NILE5 seemed to have the least direct experience with the conflict, remembering media coverage mostly but he also was aware of the security infrastructure in place when entering certain cities. The gravity of the situation was not lost on him as he alludes to an element of luck in not being caught up in any incidents. He also recalled the role of family in mitigating disruption or providing support to navigate problematic areas or situations of conflict.

Would you ever have come into town on your own or always have a support or family person?

NILE5: Yeah, I’d have had [my] brother or sister.

And did you ever say, I really want to go into town, but your brother or sister say we can’t now there’s trouble happening? Can you think were you always able to go into (named city) when you wanted to?

NILE5: I’m thinking I could, yes.

492 A Northern Ireland phrase for organizing gangs or allies to perpetrate violence, which during the Troubles was a valid and worrying threat to safety.
493 Extract from interview with NIP5, 4 April 2016, transcript on file with researcher.
Supporter: Do you remember the check points? I don't remember this but people always talked about the checkpoints coming into (named city). Maybe sometimes people looked inside people’s handbags to check inside their handbags. Do you ever remember that?

NILE5: Yes I do. 494

While NILE2 was frustrated at being limited in his movements and restriction on his social opportunities he also had examples that warranted such protective measures.

NILE2: One day I saw a bus being hijacked outside (town land) shops, me and my friend J was down and we seen the bus getting hijacked with my other friend and he thought the bus driver was burnt and all, he didn't know if they got all the people out. But they [members of paramilitary groups] just wanted to burn the bus, not the people, so he started crying. 495

The taboo nature of discussing the Troubles was very evident from NILE3 and NILE4’s responses. They gave very short answers and even with prompting from their support persons were reluctant to engage on the topic. NILE4 was the most reluctant to speak in any terms about the conflict so I attempted to approach the issue from a number of different angles, asking about police and emergency services also.

Ok, so here is kind of a harder question but you can say if you don't want to talk about it. But did you ever know anyone who was involved in the Troubles?

NILE4: No, no, no.

Did you ever have any experiences with the police?

NILE4: No.

Did you ever have an accident?

NILE4: No.

Were you ever in an ambulance?

NILE4: No.

So did it ever happen that you weren’t able to go to your service?

494 Extract from interview with NILE5, 12 April 2016, transcript on file with researcher.
495 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
NILE4: Naw.

That it was ever closed because of the conflict?

NILE4: No.

It always stayed open?

NILE4: Yes.\textsuperscript{496}

NILE3 indicated at the outset that it wasn’t a much discussed topic, ‘\textit{Ooohhh, don’t want to know}’.

Yeah, that's usually the reaction. Do you want to talk a little bit about it or do you want to stay away from it?

NILE3: Everything?

Did you know anyone who got hurt?

NILE3: I don’t remember.

Do you remember if there was ever a time that you couldn't go into town because the police were there or there was a bomb scare?

NILE3: I don't want to know. I don't want to know.\textsuperscript{497}

NILE1 had returned from the institution in a neighbouring jurisdiction and was residing in an institution in the North during the Troubles. The support person explained that NILE1’s life was more regimented due to her institutionalisation. He emphasized choice primarily – a person without a disability who was not subjected to the regime of an institution could have made their own choices about the risks of travelling to certain parts of the city. NILE1’s participation in employment was not affected in her first job due to the proximity of her accommodation (sheltered group home) to her place of work and because flashpoints for violence were confined to other parts of the city. While working in an area that was free from violence, NILE1 highlighted the importance of the bus service for her to access employment.

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\textsuperscript{496} Extract from interview with NILE4, 7 April 2016, transcript on file with researcher

\textsuperscript{497} Extract from interview with NILE3, 7 April 2016, transcript on file with researcher.
NILE1: *I loved my work. I didn’t want to go home* [to the institution].…. *When I came out of work I always got the 4 o clock bus down to (named institution), [it would] take me down [the road] and [I would] walk up then.*

When she moved to a different residence and consequently changed jobs, paramilitary actors targeting her workplace did impact on her daily life. The support person explained that this was tactical – electricity would be cut off in the area or a bomb threat made. Staff at the institution did not offer information about the cause of disruption or reasons for limiting movement of residents. Her support person provided significant background information with NILE1’s permission and she agreed with what was being said.

Supporter: *Here, you don’t mind me stepping in explaining?*

NILE1: *No.*

Supporter: *Her experience of the Troubles would have started when she moved to (second named institution).*

NILE1: *Aye. [Yes].*

Supporter: *Cos these streets would have been blocked off, there was no buses on. When she worked in (named workplace) there was nothing on in (conflict zone), (conflict zone) was a war zone and (named workplace) was 50 yards away from a no-go area. Any buses went in were hijacked and burned.*

NILE1: *I walked up.*

Supporter: *They’d have been sent home because they’d have just thrown a petrol bomb in the middle of (named workplace) and they’d have been sent home.*

NILE2 continued to give examples of how both the conflict and his disability impacted on his ability to socialize and engage with his community.

NILE2: *One other memory not being able to get to places, to town, I wasn’t allowed [to go to the town] sometimes because of things like, because of bombs and stuff.*

Ok and who would have said that you weren’t allowed to go?

*My mother. She didn’t want me [to go] up.*

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498 Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
499 Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
And she wouldn't have gone herself?

She would go when she had to but she wouldn't [otherwise]. See I just went up too because I wanted a walk 'cos I was bored after leaving school and I had nothing. Because I stood out from the crowd friends were scarce and nobody really wanted to know except to take a hand. [local slang for mocking].

NIP2 referred to the possibility that persons with intellectual disabilities were shielded from the politics and activities of their local community in relation to the conflict. This is supported by the fact that NILE1 and NILE2 said that no mention was made, or reasons given, for the conflict by their family or support staff. Similarly no references were made to being given information about the conflict by families or support persons by the other three participants.

NIP2: I think that's just an indication of how invisible the population were and in some cases you could argue how they weren’t seen as relevant to the conflict. Maybe that's a good thing, who would want to be relevant to a conflict? But it is happening in my area and affecting my people so. I’m not sure, I can’t remember hearing of any instances where people with learning disabilities would have gotten into territorial fights or fights between communities. So I don't know if that was managed differently, or maybe if I had gone to an integrated school or centre, maybe it is not that relevant to me.

NIP5 recalled how efforts were made to provide support services to persons with intellectual disabilities to ‘keep them out of trouble’ and ensure that they would not be drawn into the conflict. This resonates with the interest NILE2 expressed in belonging to a group of friends and the peer pressure of stone throwing discussed earlier.

NIP5: I don't know if we’d have any direct experience with it but we would know that, particularly, most of the people that we tend to support are people with severe learning disabilities. And probably the most able and vulnerable people are those with mild and moderate learning disabilities. The most susceptible to being influenced and also the most able to act on the influence of others. So we would have had plenty of contact with after care services who are looking for supports for children with mild and moderate learning

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500 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
501 Extract from interview with NILE1 and NILE2, 5 April 2016, transcript on file with researcher.
502 Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
disabilities who typically wouldn't get support from learning disability services. They're trying to find something to keep these guys out of trouble.\textsuperscript{503}

The reports from the lived experience participants indicate the extent of exposure to the Troubles differed regionally. The reluctance of NILE3 and NILE4 to speak on the topic are reflective of the taboo nature of the topic which remains currently. NILE1 and NILE2 recounted their experience in a casual manner and their stories indicate that the disruptions to their daily lives were common place\textsuperscript{504}. While NILE5 did not experience the violence frequently, his memories of extensive security when entering urban areas was experienced on an equal basis with the general population. The professionals provided the perspective that persons with disabilities were impacted in a different manner to the general population, which the lived experience participants did not recognise about their own lives, as it seemed the norm to them. Disability services attempted to mitigate the manipulation by paramilitary actors of the basic motivations for social connections which persons with disabilities experienced. While this is positive for the physical safety for individuals with disabilities, it reinforces protectionist attitudes as no such preventative measures were available for youth without disabilities.

3.3.10 1990s political context

Prominent during the 1990s was the issue of realising self-determination for the island of Ireland. Both the Irish and British governments agreed on the condemnation of any violence to achieve political ideals. In December 1993 the Joint Declaration on Peace\textsuperscript{505} was made public. This document was intended to lay the foundations for a path to a NI free from conflict\textsuperscript{506}. Ingrahan argues that this document facilitated the movement toward politics and away from violence for the Republican factions, albeit with considerable persuasion from leaders of Sinn Fein who championed a ceasefire\textsuperscript{507}.

\textsuperscript{503} Extract from interview with NIP5, 4 April 2016, transcript on file with researcher.
\textsuperscript{504} Extract from interview with NILE3 and NILE4, both 7 April 2016, transcript on file with researcher.
\textsuperscript{506} Ibid
In February 1995 the Joint Declaration on Peace was built upon with ‘A New Framework for Agreement’\textsuperscript{508}, which alluded to future governmental structures for NI. Importance was placed on the recognition in the Irish Constitution that a united Ireland would only occur in the event of democratic consensus in both Northern Ireland and the Republic of Ireland\textsuperscript{509}. The inclusion of all relevant stakeholders and parties to ensure all communities were participants in the future peace process was prioritized. In reality however, this was cause for considerable concern, as decommissioning of weapons was deemed a pre-requisite for a place at the discussion table\textsuperscript{510}. The resolution to the standoff between paramilitary parties came in the form of the independent American intervention, by the then President Bill Clinton, who visited NI in late 1995. On the eve of his arrival Irish and British negotiations brought about the Joint Communiqué in which they pledged to continue the pursuit of inclusive talks and decommissioning concurrently\textsuperscript{511}. At the same time it was agreed than an independent body to monitor decommissioning would be established\textsuperscript{512}. Clinton endorsed this policy but the British government did not adhere to the recommendations made by the independent decommissioning body\textsuperscript{513}. The election of the Labour party to government in 1997 was welcomed by Republicans as this was anticipated to reduce reliance by the British Government on Unionist support, and decommissioning was then brought to the fore of discussions between Irish and British government\textsuperscript{514}.

Parallel to this, republican politicians realized the willingness of the parties involved in the process to include Sinn Fein. Statements encouraging a lasting peace from prominent leaders of the republican and civil rights movements, Gerry Adams and John Hume, had the desired effect of persuading the IRA to continue with a ceasefire in June 1997\textsuperscript{515}. However, violence by smaller groups on both sides continued and these put the position of Sinn Fein and the

\textsuperscript{509} Ibid
\textsuperscript{512} Ibid
\textsuperscript{514} Hayes, B.C., McAllister, I., ‘Sowing Dragon's Teeth: Public Support for Political Violence and Paramilitarism in Northern Ireland’, Political Studies (2001) Vol. 49, Iss. 5.C
Democratic Unionist Party as participants in the talks in jeopardy. The issue of how power would be divided in the new proposed NI Assembly as well as the contribution and influence of the Irish government dominated the difficult talks in the run up to the agreed deadline of 9 April 1998. This deadline was not reached but parties continued their efforts and 10 April 1998 (Good Friday) heralded the conclusion of the multi-party talks.

3.3.11 Legislation and policies on disability during the 1990s

The 1991 Census of Northern Ireland continues to include persons with disabilities under the ‘Totally Economically Inactive’ category, without disaggregating this data further to capture how many persons with disabilities in general, or persons with intellectual disabilities in particular are included in this category. From a brief overview of this data the numbers of Catholics unemployed due to ‘Long Term Sick and Disabled’ are high compared to that of their Protestant counterparts.

Greer asserts that there were highly significant reductions in demand during the conflict for some health and social services connected to suicide, drug abuse and mental health disabilities during the conflict but acknowledges the delayed impact on sufferers and the huge increase in need for these services in the aftermath of the conflict.

Campbell and McCrystal conducted surveys of social work professionals who worked in NI during the Troubles to determine how the health service fared at the time. They note that the lack of health and social services during the conflict is acknowledged in the Good Friday Agreement as an area of concern. Their research indicated that there were disruptions to services arising primarily from bombings and the personal performances of health and social service workers.


520 Ibid. There are 34,800 males in this category. 14,605 of these are Catholic while the remaining 16,934 identify as Presbyterian, Church of Ireland, Methodist or Other.


523 It is mentioned under Strands 2 and 3 of the Good Friday Agreement and is highlighted as an area for North-South cooperation.
staff were affected by sectarian harassment. Compulsory admissions to psychiatric hospitals which required police support were also limited during the conflict, as the police service were occupied with other aspects of law enforcement. Campbell and McCrystal’s findings on the disruption to public health services resonate with the qualitative research undertaken for this thesis. The professional group provided examples of difficulties for staff and service-users attending day centres, sectarian tensions between both staff and service-users and the harassment of staff by family members of service-users.

The Disability Living Allowance in 1992 replaced the payments discussed at Section 3.2.6 and was considered to be a more equitable payment\(^524\). In terms of the progression of disability rights in Northern Ireland towards the end of the conflict, the Disability Grants Act 1993\(^525\) provides for the granting of monies to the Independent Living Fund by the Department of Health and Social Services. The original fund established in 1988 was restructured in 1993\(^526\). The change related primarily to the increased role of local authorities in the administration of the fund\(^527\). In order to be eligible for accessing the fund, the support required by the individual had to exceed that available solely through the local authority and applications could only be made with the endorsement of a local authority. Since 2015, 500 persons in receipt of Independent living fund in NI obtain a similar payment through ILF Scotland\(^528\) but the fund is not available to any new applicants.

However, arguably the most significant policy document on the delivery of disability services towards the end of the conflict is the Department of Health and Social Services’ ‘People First: Community Care in NI in the 1990s’\(^529\). This document indicates a partial incorporation of the ethos of the U.S. Independent Living Movement as it highlights the benefits that result from community based care for the elderly, persons with physical and intellectual disabilities and persons with mental health disabilities. However, the emphasis remained on the role of the health authorities rather than the provision of financial assistance for individual service-users to decide on the supports they choose to purchase. There are considerable positive

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\(^525\) Chapter 14, Disability Grants Act 1993.


\(^527\) Ibid at p.93.


aspects to the report. It emphasises the necessity of cross-departmental cooperation for effective implementation. The report relies on a number of concepts borrowed from ‘Community Care: Agenda for Action’\textsuperscript{530} including the promotion of respite services, support for carers, high quality assessment and case management in all services, promotion of independent sector service providers, increased clarification and accountability for agency roles and ensuring value for tax payers money\textsuperscript{531}.

As noted earlier in this chapter\textsuperscript{532}, the information available on the prevalence of persons with disabilities in NI is limited and no disaggregated information is available from the census. However, the 1990 publication ‘People First’ recorded 7,300 people had a ‘mental handicap’ in Northern Ireland and noted that 70\% of these lived at home\textsuperscript{533}. The target of reducing the amount of people with ‘mental handicap’ residing in institutions to 20\% indicates that they recognise the relatively high levels of institutionalisation\textsuperscript{534}. The state was also very reliant on the work of carers in the home to provide support for persons with intellectual disabilities. ‘People First’ proposed increases in respite for carers and families, especially of young people with disabilities. References were also made to the increase in employment training programmes and day centres, although the report is critical of the administration of day services that do not contribute to the continuous educational development and engagement of users\textsuperscript{535}.

Throughout the ‘People First’ report there are limited provisions relating specifically to persons with ‘mental handicap.’ Chapter 4 of the report provides in-depth detail about the procedures involved for the assessment of individuals’ needs through cross-departmental evaluation and the assignment of services and resources as appropriate. Housing associations were referenced as the predominant residential arrangements for persons with disabilities not living with families or in traditional segregated institutions\textsuperscript{536}. The report suggests that considerable and concerted efforts were made by Department of Health Social and Personal

\textsuperscript{530} Discussed earlier at Section 3.3.7.
\textsuperscript{532} 1966 Census discussed at Section 3.2.2 and 1981 Census discussed at Section 3.3.8.
\textsuperscript{534} Ibid
\textsuperscript{535} Ibid
\textsuperscript{536} Ibid at p.38. NILE3 spoke of her current accommodation which was described as similar to a housing association. 7 April 2016, transcript on file with researcher.
Services to identify the positive and negative aspects of disability services in NI during the 1990s.

The Disability Living Allowance and Disability Work Allowance Act 1991 provided for social security payments to facilitate care and mobility costs connected to a person’s disability. This Act does not extend to NI in its entirety but the substantial content of the Act was made applicable to Northern Ireland via the Disability Living Allowance and Disability Working Allowance (Northern Ireland) Order 1991. The provisions in Northern Ireland facilitated payments for persons with intellectual disabilities who required a carer for their day to day activities.

As demonstrated from the partial applicability of legislation above ensuring inclusion of NI in the remit of legislation applicable in the UK was an extremely difficult battle. Activist Morgan credits Rev. Martin Smith537 for his role in ensuring disability legislation in the UK was equally applied or extended to NI. This is indicative of how intricately woven together religion and politics were at the time in advancing any social or legislative reform. An example of legislation which Rev. Smith campaigned for to apply equally in NI was the Civil Rights (Disabled Persons) Bill 1994538. The legislation was described by Roll as having the potential to bring Britain on a par with disability equality legislation as Australia and Canada539. Legislation demanding such civil rights standards would have had a positive impact in Northern Ireland. The Bill was designed to provide protection from discrimination in the areas of employment, provision of goods and services and establish a Disablement Commission to investigate claims of disability related discrimination. It was drafted against a backdrop of major organisation and lobbying among disability activist groups and its shelving in favour for the Disability Discrimination Act 1995 was viewed a major blow to the efforts of these parties540. Milward541 describes how excessive amendments to the proposed Bill at the third day of reading led to its demise. Its replacement, the Disability

Discrimination Act 1995, applied to NI equally. However, many activists and scholars are critical of the 1995 Act in comparison with the proposed 1994 Bill. These developments were also commented on by participants in my qualitative research as follows:

NIP2: [T]he other thing that obviously happened would have been the Disability Discrimination Act and again it would have been brought in I think, one of the first laws that the Northern Ireland Assembly passed, couldn't swear on that. Even though it was a mirror image of what was happening in England and probably disappointing in terms of its strength and what it could do. But I guess it was a step in the right direction, and it introduced that concept of reasonable adjustment and whether you think that's the right approach, or sufficiently rights-based, I don't know.

NIP4 also asserted that the Disability Discrimination Act 1995 provided for the establishment of the NI Disability Council. This Council was subsequently merged with other thematic monitoring bodies to create the Equality Commission in the wake of the Good Friday Agreement. While NIP4 accepts that the Northern Ireland Disability Council was operating on weak legislation and did not have much time in operation to achieve any meaningful results, she indicated that the Disability Council had collaborated with civil society organisations and that modest progress had been achieved in advancing disability rights through these initiatives.

NIP4: We were part of a disability movement campaign to get the DDA [Disability Discrimination Act]. We ran a very successful disability movement as a whole, ran a very successful campaign to get civil rights for disabled people, so that pre-dated 1998.

Disability policies developed by the Department of Health, Social and Personal Services was influenced by the progression in the UK during the 1980s in recognising the importance of community living and transitioning people from hospitals. While the financial supports available were equivalent to those available in the UK there was no indication from literature

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542 Ibid
543 Extract from interview with NIP2, 22 March 2016, transcript on file with researcher
544 Disability Discrimination Act 1995, Section 50, Part VI outlining the powers of the Council as broadly similar to that of a domestic human rights monitoring instrument – advising government on legislation and policies but limiting such powers by having regard to the financial implication of any recommendations but it does have consultative powers, to which MP made reference. The most recent version of the legislation – Disability Discrimination (Northern Ireland) Order 2006 refers to the Equality Commission instead of the Council at Part VI. Extract from interview with NIP4, 4 April 2016, transcript on file with researcher
545 Abert, C., and Lang, P., ‘The Peacebuilding Elements of the Belfast Agreement and the Transformation of the Northern Ireland Conflict’, Frankfurt am Main, Germany, 2009 at p.104.
546 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
or the interviews of the equal availability of personalised supports. Legislation during the 1990s was weak and the monitoring mechanisms for disability rights was short lived. However, NIP4 was positive about the engagement with civil society by the Northern Ireland Disability Council and the introduction of the requirement for reasonable accommodation for persons with disabilities. The Troubles continued with numerous attempts to re-establish self-governance structures in NI and to end the violence which will be discussed next.

3.4 Section 3 Peace Process (1998-2008)
Section 2 has outlined the fractured political initiatives to secure talks among parties representing Unionist and Nationalist communities along with input from the Irish, British and American governments. Section 3 will now provide detail on the nature of the culmination of these efforts and the legislation and policies relating to disability which occurred in the decade after peace was agreed.

3.4.1 Good Friday Agreement 1998
The text of the Good Friday Agreement enshrined in the Northern Ireland Act 1998, served as the foundation for human rights and equality in the new political climate, as well as setting out the administrative and political framework for NI. Part VII relates to human rights and equal opportunities and governs the establishment of the Northern Ireland Human Rights Commission and the Equality Commission Northern Ireland as National Human Rights Institutions. The Good Friday Agreement was mentioned numerous times by the professionals and participants with lived experiences as a key turning point for persons with disabilities, including persons with intellectual disabilities being recognized in terms of equality. In particular Section 75 of the Northern Ireland Act 2000 was credited with having a role in this change of mind-set.

3.4.2 Section 75 Northern Ireland Act 2000
Section 75 was referred to most of all among participants with experience in disability support services as the most significant legislative development for persons with intellectual disabilities. Section 75 (1)(a) of the Northern Ireland Act specifically identifies disability as an area in which public authorities must promote equality of opportunity in the disposal of

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547 Discussed at Section 2.3.3.
548 These bodies have also remained as separate institutions despite the trend of merging such institutions in neighbouring jurisdictions. The former Irish Human Rights Commission and Equality Authority was merged as the Irish Human Rights and Equality Commission in 2014, [https://www.ihrec.ie/about/ihrec-act-2014/](https://www.ihrec.ie/about/ihrec-act-2014/) accessed 21 March 2017.
their duties and this can be argued as the provision of adequate support and assistance services.

‘A public authority shall in carrying out its functions relating to Northern Ireland have due regard to the need to promote equality of opportunity—

(a) between persons of different religious belief, political opinion, racial group, age, marital status or sexual orientation;

(b) between men and women generally;

(c) between persons with a disability and persons without; and

(d) between persons with dependants and persons without.’

While acknowledging the limitations of the provision, NIP2 spoke positively of Section 75 as equipping persons with disabilities and their advocates with some means of disability proofing state policies.

NIP2: To me the most of powerful tool in terms of the change in concept and ideas about people was in our Equality legislation and that's section 75 of the Northern Ireland Act 1998…..Section 75 in itself is actually quite weak ..... [I]t said all policies the government did or any of its agents did, had to be screened to say were they going to have an adverse impact in any way on any of those nine categories or groups. And one of those categories were an adverse impact on disabled people compared to non-disabled people. So the first time we were able to have a level playing field - the policy you have is having an adverse impact. That to me was a really powerful statement and a really powerful tool to be used, not in a law making way as in holding people to account but in persuading people that people with disabilities are rights holders. And in fact there was a distance between what rights everybody else would enjoy and what rights people with disabilities would enjoy. So we worked quite hard with the Equality Commission, a part of what we tried to do was to draw attention of the public bodies and the Equality Commission at the time to how different the lives of people with disabilities were.

NIP4 was more reserved about the impact of Section 75 but acknowledged its role in achieving a recognition of equality for persons with disabilities which the Disability Discrimination Act had not had the longevity in NI to achieve. NIP4’s criticisms are useful for the operation of similar initiatives in other countries.
And do you think section 75 is working well?

NIP4: No… it started right and then it just became a tick box exercise. In the beginning it meant something…. the peace process with a rights framework and section 75 changed the status here of people with intellectual disabilities…. In Northern Ireland it had more impact than the DDA, because the DDA hadn’t had time to play out…[Section 75] called for engagement with people and that meant we helped with putting people out there and providing support that made that successful. And that really changed the status of people.549

NIP3 associated Section 75 as having a role in fulfilling UNCRPD requirements:

NIP3: [T]here is obviously the general requirement in the Equality Act about the community impact and different things like that under Section 75 where persons with disabilities are a recognized group. So their rights are being considered in that process.550

NILE2 was the only participant with lived experience who indicated that he was aware of Section 75 and it was clear that involvement in an advocacy group helped him to relate the equality dimensions of the peace process to his own circumstances.

Do you know about the peace process then, how it all ended?

NILE2: Just, I know the jist [basics] of it. The Good Friday Agreement in 1998 - they all had to sit down together because they both realized they weren’t going to win. Both sides realized they weren’t going to win the war so they all sat down together and after much disagreements and deliberation and whatever else, there was an agreement. And section 75 of the agreement is where the disability section. It means we have to be treated as equally as possible.551

NILE2 also demonstrated knowledge on the key figures from the time and he was more confident in his first-hand knowledge of the peace process than the Troubles.

Do you know who the politicians were that were involved in the peace process?

NILE2: Well you had Ian Paisley. You had Gerry Adams. I think at the time you had Tony Blair and before that John Major. But I didn't think John Major played a part in it. You had

549 Extract from interview with NIP4, 4 April 2016, transcripts on file with researcher.
550 Extract from interview with NIP3, 30 March 2016, transcripts on file with researcher.
551 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
Tony Blair then the Unionist sides, Peter Robinson and Ian Paisley Senior. You know, the top people like that. I don't really know much about politics.

And did you know who those people were at the time?

NILE2: Well I knew that Gerry Adams was the leader of Sinn Fein, and I think he still is. I knew that Ian Paisley, God rest him was a member of the DUP, the leader of the DUP actually. That's, and I knew Gerry Adams, and I knew Martin McGuinness was from Derry so I knew all the main players. 552

However when it came to voting on the Good Friday Agreement NILE2 indicated that he did not feel well enough equipped with information but was satisfied to make a decision with the information that he had, with an end to the conflict being his main priority.

Yeah, so there was a referendum, whenever they came up with the Good Friday Agreement people in NI had to vote on it. Did you vote for that?

NILE2: Yeah, they accepted it. I voted yes. Well I didn't really know what I was voting for at the time. I know that 71.1% of people voted for it, accepted it, making it official.

And you were one of them?

NILE2: I was one yeah.

So who helped you, how did you come to your decision about that if you don't vote about other things?

NILE2: Well I felt that this one was particularly important because it's to save the future of the province. So I just decided on this occasion to vote for.

At the time, you said you knew about politicians, but did you know about the police or would there be changes to health? Did you know about what the government would do once you voted them in?

NILE2: I knew there would be peace once we voted. But see all the other stuff you're talking about, policing, it sort of didn't interest me to be honest and I think that's characteristic of

552 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
most people like me with learning disabilities, the wouldn't be interested in them things there. Well that's only my opinion...

NILE1 was also aware through attendance at an advocacy group of participants in the peace process and responded to questions with prompting from her support person.

Do you know then about the peace process? After that - about the Good Friday Agreement?

NILE1: Yeah, the Good Friday agreement.

What age would you have been around then?

NILE1: Oh I can’t remember.

1998? Maybe in your 50’s?

NILE1: Aye. [Yes]

So how did you find out about it? Did you hear about it on the news?

NILE1: I heard it on the news aye.

And did you think it's a good thing or a bad thing?

NILE1: It was just the way the Troubles went.

So do you know who the main people involved in it were? Who the politicians were?

NILE1: I don’t know.

Supporter: Well you’ve met two of them.

NILE1: Where?

Supporter: Here.

NILE1: Gerry Adams and Martin Mc Guinness.

Supporter: Yes, the very first one, the first two that went to Belfast, you've met both of them. You've met Gerry Adams in here. Who’s the other one? The big one?

NILE1: John Hume

Supporter: All of our groups have met...

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553 Extract from interview with NILE2, 4 April 2016, transcript on file with researcher.
Oh wow!

NILE1: John Hume, he was involved, he was an MP.

So how did you meet him?

NILE1: I met John, I’d seen John on TV and the news and all. And he brought President Clinton to Derry.554

Unlike other participants NILE1 was the only person to respond neutrally when asked whether she considered the peace process to be good. This is surprising when considering how personal her recollection is about meeting key figures in the peace process – using first names and being very casual in her interactions with them. There seemed to be elements of relatability and participation when discussing the politicians.

NILE4 was not very interested in the topic of the peace process. She did not indicate having any meaningful engagement with the peace process, made no reference to participating in the Referendum and only acknowledged that the media was the main source of information on this topic555. NILE5 was comfortable speaking about the peace process but his information was limited and relied on the media, as did his contributions about the conflict itself556.

NILE3 was equally hesitant to engage on the topic of the peace process but similar to NILE4, she was familiar with it from media reporting. NILE3 had the sad experience of losing a family member to violence in the aftermath of the Good Friday Agreement. This understandably contributed to her not wanting to discuss the topic in any great detail557. Her support person prompted her to discuss an event which happened in the locality.

NILE3 support: Where did you hear about the (incident) and stuff like that?

NILE3: I was there with my mammy.

You were there with your mammy?

NILE3: Aha, and then coming out then I heard a noise and came home and started to cry.

554 Extract from interview with NILE1, 5 April 2016, transcript on file with researcher.
555 Extract from interview with NILE4, 7 April 2016, transcript on file with researcher.
556 Extract from interview with NILE5, 12 April 2016, transcript on file with researcher.
557 Earlier in the interview she had light-heartedly implied that she didn’t want to talk about the Troubles. ‘Ooohhh, don’t want to know.’ Because of this had not pursued questions relating to the Trouble’s and had not expected such an experience to arise from a post-conflict related question. The revelation of the death of NILE3’s sister during the post-conflict period was surprising to the support person also.
Support: So you were scared then.

NIL3: And then my sister was in the middle of it. She died of it.

Your sister died in it, did she?

NIL3: Yeah.

Sorry to hear that.

That’s alright, I don't want to talk about it anymore.558

NIP1 suggests that disability was not a consideration in the peace process, despite the focus on victims who have been injured, or now live with a physical disability, as a unifying issue for encouraging cross-community collaboration and moving the peace process forward.

NIP1: It just hasn’t been considered in the context of the conflict. Even though a lot of people who are now disabled were disabled as a result of the conflict, that hasn’t been on the agenda with politicians and policymakers. Their focus has been on victims and there has been no recognition of the relationship between some individuals who have been injured during the Troubles and what that means in disability terms559.

NIP4 also referenced the non consideration of persons with intellectual disabilities in the funding streams which were made available for positive cross-community initiatives in NI after the Troubles.

NIP4: The other benefit of the post conflict times was the peace funding. That made a lot of things possible that wouldn't have been possible otherwise. Because the only services about were from services, and services are about placements. They’re not about capacity building. Whereas the peace process gave capacity building money which made it possible to get self advocacy going and to give people the experience of engaging with politics, to take part in political process. Without the peace funding that wouldn't have happened. Or it would have been much much slower.

So is that the pot that Ireland, everyone put into? America as well?

558 I gauged NILE3’s demeanour and she was not upset. I confirmed that she was comfortable to continue with the interview. I immediately moved on to the next topic of questions.
559 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
NIP4: Yes, that everyone put into. Because a lot of that was about social inclusion and political participation. So we used that pot to get funding and make the case for and demonstrate inclusion and political participation of people with intellectual disabilities. And it wouldn’t have happened without that same money. Without that thinking and without that money.

So do you think, I know my school benefited from that being on the border, but it was a sectarian thing. Did you have to fight or argue in that it was going to reduce sectarian tensions?

NIP4: Yes, we had to do that yes. Exclusion was also a good enough argument some of the time. But it changed. Peace 1 exclusion was good enough, Peace 2 it became something else and by Peace 3 we weren’t able to access it. It became in accessible as it was more narrowly focused on sectarianism. You could still make the case but with such small numbers of people but we couldn’t win in a grant round.

Overall, the peace process was welcomed by the participants with lived experience. The Good Friday Agreement promoted equality and human rights, a core element of the campaign demands of the Civil Rights Association in the 1960s. The peace process did not result in an immediate cessation of violence, as NILE3’s experience of the death of her sister evidences. In terms of advancing the rights of persons with intellectual disabilities, Section 75 was deemed to be significant in addressing a cultural shift to recognise persons with intellectual disabilities as rights holders. NILE2’s knowledge on the subject of Section 75 and how it relates to his experience does suggest Section 75 has been positive at an individual level, although NIP4 notes that it has not been used to the full extent of its potential. This chapter will now discuss the administration of disability services in Northern Ireland in the aftermath of the conflict in light of the peace process.

3.4.3 Overview of the current health service

In the aftermath of the Good Friday Agreement, disability legislation and policy has come under the remit of the Office of the First Minister/Deputy First Minister in Northern Ireland, while the administration of disability services is the responsibility of the Department of Health, Social Services and Public Safety.
New policy developments emerged following the conflict which acknowledged people with intellectual disabilities as valued citizens. ‘Health and Wellbeing into the next Millennium, the Regional Strategy for Health and Social Wellbeing 1997-2002’ in NI acknowledged that the de-institutionalisation initiatives for people with learning disabilities resulted in highly staffed accommodation and that integration into community was difficult but experiences were ‘less institutional in character’. This strategy also outlines the achievements to increase community based care and notes that these been successful for people with learning disabilities. The issue of advocacy for people with learning disabilities also emerged in this strategy in the context of being empowered to make informed decisions about their lives. The current Department of Health, Social Services and Public Safety was established in 1999 by the NI Executive through the Northern Ireland Act 1998 and the Departments (Northern Ireland) Order 1999. It comprises various branches to ensure an integrated health and social care service. The Health and Social Care Board is in charge of service delivery and performance management as well as identifying the future needs of the population through five Local Commissioning Groups.

The Public Health Agency is jointly responsible with the Care Board for the delivery of an integrated plan through Health and Social Care Trusts within NI. The Patient and Client Council provides an independent voice for patients, clients and carers within the health system. This could prove an important role in advocacy for persons with intellectual disabilities. The Regulation and Quality Improvement Authority is responsible for monitoring and enforcing high standards of services, including residential institutions for adults with intellectual disabilities. Further monitoring is implemented through the NI Social Care Council which regulates the social care workforce to benefit providers and

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561 Ibid at p. 5.

562 Ibid at p. 70.

563 Ibid at p. 87.


565 Ibid

566 Ibid

recipients of such services\textsuperscript{568}. There are other branches relating to the training of medical professionals such as midwives and dentists as well as the business, legal and human resource elements of the DHSSPS but these are not particularly relevant to this discussion of independent living for persons with intellectual disability.

3.4.4 Post conflict disability legislation

A host of legislation was enacted by the new NI Assembly of relevance to persons with intellectual disabilities. The Human Rights Act 1998 did not come into force until 2000 but it incorporated the ethos and provisions of the ECHR into the operations of NI’s governing bodies. One example of this affects the duty on the public authority (under Section 75), as discussed above, to ensure that it operates in a manner consistent with the ECHR. The Law Centre of Northern Ireland\textsuperscript{569} identifies the core elements of the Human Rights Act applicable to persons with intellectual disabilities as the right to freedom from torture (Article 3) and right to respect for private, family and home life (Art 8(1)). However, they note that this right can be interfered with on a narrow range of justifications (Art 8(2))\textsuperscript{570}.

The Carers and Direct Payments (Northern Ireland) Act 2002 created a new Direct Payment scheme which widened the net of eligibility for the scheme to include those identified under the Chronically Sick and Disabled Persons (NI) Act 1978 and the Health and Personal Social Services (NI) Order 1972. However, some participants in the qualitative research undertaken for this thesis were critical of the implementation of this legislation to promote the use of direct payments in Northern Ireland.

NIP5: That's only really starting. We've been doing some of that. Some of that before it took off, it's only just beginning to take off now. That's interesting because it is evolving. I was going to say it was a bit money driven and they had £10 an hour to buy services when you can’t buy services for £10 an hour. Because it costs more money than that. We found out recently that £10 an hour is just a starting amount, you can get more than that if you ask. But it is not up to us to ask, it's up to the individuals or family. So it is all, one has the impression it's being thought up as it goes along, which is a bit odd considering it has been going on in the UK for the last ten years or so\textsuperscript{571}.

\textsuperscript{568} Ibid
\textsuperscript{570} Ibid
\textsuperscript{571} Extract from interview with NIP5, 4 April 2016, transcript on file with researcher.
In 2002 national research on intellectual disability legislation, policy and services was conducted in NI. It was known as the Bamford Review. NIP2 referred to this work as significant, but noted that there was a lack of funding to ensure recommendations from the research were implemented.

NIP2: [Y]ou asked about the significant reports, the Bamford Review was a very significant thing. It didn’t achieve its potential because it wasn’t funded. Perhaps it was too ambitious and too complex. Perhaps a simpler exercise would have been more effective in the end. But it was an honest attempt to really make recommendations that would make a difference. If it was resourced with the same kind of honesty, even if it was resourced to a lower level. If the pattern of resourcing had been agreed and a system of prioritising. Instead it just became more of the same. It didn’t affect the changes.  

In 2004, the NI Executive established the Policy on Social Inclusion on Disability Working Group. The remit of this group was to examine the barriers to participation in society for persons with disabilities. This is significant considering that it was not until 2008 that a similar UK wide initiative (which did not include NI) known as the Independent Living Strategy was published with the aim of addressing the gap between rhetoric and real experiences in relation to disability. The recommendations of this Group formed the foundations for the Strategy to improve the lives of people with disabilities 2012-2015. These included cross departmental collaboration encouraging employment without risk of loss of benefits and improving public attitudes to achieve social inclusion.

Equal Lives was published in 2005 and this was a continuation of the research being conducted by the Bamford Review Group in 2002. It aimed to influence the design of services and policies for people with learning disabilities in NI over a 15-20 year timeframe. NIP2 was the only professional to make reference to this document during a discussion of

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572 Extract from interview with NIP2, 22 March 2016, transcript on file with researcher.
574 This will be discussed further at Section 3.5.1.
current policies, so its impact may be viewed as limited in terms of shaping disability policy and practice in Northern Ireland.

A Human Rights and Equality of Opportunity Committee within the DHSPSS was established in 2006 to evaluate the human rights and equality nature of the Bamford Review going forward. Difficulties in public perceptions of capacity, lack of accessible information, the exclusionary nature of mainstream services such as education, transport, employment were identified by the Committee as contributory factors to the denial of rights to persons with intellectual disabilities in NI\textsuperscript{577}. The Committee’s 2006 report refers to the role of advocacy services in ensuring human rights and equality of opportunity for persons with intellectual disabilities. It describes how advocacy can vary from identifying someone to assist an individual, to the provision of accessible information or the facilitation of groups of affected people to effect change on issues important to them. The report is critical of the haphazard development of advocacy services throughout NI, citing staff and relatives as primary advocates for people with learning disabilities, rather than recognising people as self-advocates. The report suggests following the lead of European trends of recognising a wide variety of models of advocacy to ensure respect for the rights of people with learning disabilities in Northern Ireland.

‘Promoting the social inclusion of people with mental health/learning disability’ was published in 2007\textsuperscript{578} by the DHSSPS. This review is complimentary to the Human Rights and Equality of Opportunity report and encourages inter-departmental collaboration. It also places disability in the mainstream of social considerations, linking the objectives of disability inclusion to the Promoting Social Inclusion Initiative and the Targeting Social Need policy\textsuperscript{579}.

In 2008, Collins and Pinkerton\textsuperscript{580} identified NI as the United Kingdom’s jurisdiction with

\textsuperscript{579} Melaugh refers to the TSN policy as initially introduced in 1991 as a conservative party effort to tackle differences in socio-economic situations of Catholics and Protestants. It was then relaunched in 1998 after a white paper entitled ‘Partnership for Equality’ and the New TSN was included in the Good Friday Agreement’s socio-economic commitments. Melaugh, M., Policy- Targeting Social Need, CAIN Web Service, <http://cain.ulst.ac.uk/issues/policy/tsn/> accessed 16 April 2014.
highest levels of social need. They argue that the 1997 Labour government policies of focusing on employment through socially responsive programmes could not be as effective in NI due to reduced employment options in the jurisdiction. While this article does not have a disability focus it does provide useful context in which persons with intellectual disabilities are socially excluded and marginalised. This was also suggested by numerous professional participants. NIP1 suggested the conflict let to paternalistic attitudes towards persons with disabilities, as well as lack of progress on other social issues.

NIP1: *I think it’s because the focus here has always been on the conflict. And now post conflict, anything else is seen as secondary. It’s quite similar if we look at children and young people. If we look at other groups, women’s groups, LGBT groups have now started to have a much stronger voice in terms of protesting. For disabled people, I think there is a general lack of awareness of the social model of disability because of the role of the church and the role of health organisations and services. The role of family. They’re very protective here compared to other parts of the UK. So I guess disabled people tend to be wrapped up in cotton wool a lot more here than in other jurisdictions and that has had an impact.*

This is re-iterated by NIP3: *With the conflict being the preeminent force, issue, because it matters, then with bread and butter issues, and people with disabilities were pushed to the side* 581.

NIP4 is critical of the lack of targeted action to address the multiplicity of exclusion which persons with disabilities may encounter in the aftermath of the conflict.

NIP4: *And the other thing that has drowned out exclusion of people with intellectual disability has been the poverty agenda. Because poverty and social exclusion, the two European policy pillars were the responsibility of the same government department – OFM/DFM. And their view was the rising tide raises all boats. And they couldn’t see that it doesn’t [benefit everyone]. Yes poverty is an issue and it’s an issue for persons with intellectual disabilities and their families. But it’s not the only issue. Exclusion is related to poverty but it isn’t only poverty. Exclusion exists even for affluent people and they are in need, they also need help that wasn’t seen* 582.

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581 Extract from interview with NIP3, 30 March 2016, transcript on file with researcher.
582 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
3.4.5 Post conflict living arrangements

This section will discuss how the policies and legislation is reflected in the living arrangements of the five participants with lived experiences. Increased independence would be expected to occur as the life cycle progressed. However, this was not reflected in the contributions. Table 8 below demonstrates the participants’ current living arrangements.

Table 8. Post conflict living arrangements

<table>
<thead>
<tr>
<th>NI post conflict living arrangements</th>
<th>Institutionalisation</th>
<th>Independent Living service</th>
<th>Residing with family</th>
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</thead>
<tbody>
<tr>
<td>Gender</td>
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<tr>
<td>Male</td>
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<tr>
<td>Female</td>
<td>2</td>
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</table>

NILE1 remains institutionalised although her place of residence has changed. She indicated that there was no consultation with service-users by the authority deciding to move residents to a new building. The move has caused disruption to being able to access public transport and as a corollary to this, NILE1 is more restricted in being able to access the community and attend events in the evenings. NILE2 indicated that he had experienced institutionalisation periodically during his adulthood but now resides with immediate family members. He was a voluntary resident within these institutions as he acknowledged his periodic need for mental health services but was frustrated at the lack of free movement around the grounds of the facilities, which fluctuated from one staff member to another. NILE3 had resided with her family in her youth and during the Troubles but had moved to a supported living service in the last decade. While NILE3 viewed the move as positive, the features described correspond to that of institutionalisation – lack of choice and control over basic daily decisions such as meal options and restrictions on accessing services in the community. She lives with nine other persons with disabilities who are supported by in-house day and night staff. She indicated being stressed and unhappy with the arrangement to start with, but as her parents had sold the family home she had no alternative. This suggests that better supports could have been provided to prepare and assist NILE3 during what is a daunting period of change in anyone’s life. NILE4 and NILE5 live with their siblings and enjoy strong bonds with their extended families.
All participants reported interacting with disability services and having networks with social, education and employment opportunities. This indicates that there has been little change in the role of families providing supports as the alternative to institutionalisation as was noted in the 1990 People First Report\(^5\). There were examples among the participants of partial Article 19 compliance in the living situations of the participants. The participants residing in the community experience more choice on their daily activities and places of residence than the two participants who reside in institutions. However, they are reliant on ageing relatives for support and they attend segregated social activities. No participant had a personal assistant or availed of assistive technology to support them to live independently but the participants all reported being satisfied with their current arrangements and were reluctant to seek to change them in the future.

As is evident from the legislation discussed above, significant strides were made in the years following the resolution of the conflict immediately preceding ratification of the UNCRPD in NI and throughout the UK to modernise the legislative protections afforded to persons with disabilities. However, these developments have had limited impact on the day to day lives of persons with intellectual disabilities in Northern Ireland, as reported by participants with disabilities and professional participants in this qualitative research.

3.5 Section 4 Post UNCRPD Ratification (2009 – Present)

While human right were a prominent feature of the rhetoric surrounding the Good Friday Agreement and considerable funding was provided to promote positive cross-community relations, the focus remained on ethnic tensions. As NIP2 and NIP4 had suggested, persons with intellectual disabilities were not considered to have the prejudices of their ethnic community and so were excluded from these initiatives. Section 75 of the Good Friday Agreement does recognise disability as a ground of discrimination but UNCRPD was the first overt recognition of the rights of persons with disabilities in the post-conflict setting. This section will examine the legislation, policies and contributions from the qualitative research about the immediate impact of UNCRPD and how it influences the lives of persons with intellectual disabilities today.

3.5.1 Ratification of UNCRPD

The ratification by the UK government of the UNCRPD in June 2009 meant the Convention was also ratified in NI. Since then, the UK Office for Disability Issues has been mandated to liaise with other relevant bodies including the regional National Human Rights Institutions to implement the UNCRPD.

When questioned on their perceptions of the impact of UNCRPD on NI, I received very mixed responses from professional participants. The lived experience participants were asked if they knew about human rights, and if they indicated yes, I further questioned about UNCRPD. However, only NILE2 indicated that he was familiar with UNCRPD enough to gauge the difference it had on his life. NILE5 and NILE1 both agreed that life had improved for them since their childhood.

NIP1 outlines the complex situation of UNCRPD not having been incorporated into domestic law and the lack of expertise within government departments on the implications of UNCRPD on their work.

NIP1: UNCRPD is obviously the broad overview even though it isn’t part of domestic law. Generally government departments are trying to see what it means to them, if the legislation is compatible with that.....Even within part of UK, there has also been a need to raise awareness of Northern Ireland in Great Britain. In the development of the first state report [report to the Committee on the Rights of Persons with Disabilities], the first draft, there wasn’t a lot of receptiveness to paying much attention to Northern Ireland. There is very very little within that. That’s something that people are concerned here that people are more focused on what is going on in England, Scotland, Wales, at the expense of what is happening here.

NIP4 flagged the slowly evolving nature of UNCRPD and the limited attention it has received from the NI government and added that there has been no impact experienced by persons with intellectual disabilities on the ground.

NIP4: UNCRPD hasn't really had much impact here. I was going to say I think the impact to the extent that I think the government is starting to pay attention to it.....But I think it's because they've been criticized, the UK is now under scrutiny for the Committee. It still

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584 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
585 Extract from interview with NILE1, 5 April and NILE5, 12 April 2016, transcript on file with researcher.
586 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
means it’s having an impact but in terms of the impact it could have had on, it’s been very low awareness in general, in the sector as a whole. I think a very low awareness at the top table, probably at the most senior levels you have awareness, further down you don’t have much.  

This view was reinforced by NIP5 who failed to see the impact among service-users in his daily work.

Would it [UNCRPD] have reignited disability as an issue or did it do anything at all?

NIP5: I don’t know. I mean it’s very difficult, I’m not sure. Certainly nobody I would have met with a learning disability has said, has ever talked to me about those things.

What about service providers, would it be on their radar?

NIP5: It’s about covering your backsides and that’s the main thing would seem to be.

In contrast to NIP4 and NIP5, NIP3 reported that there has been some impact of the UNCRPD on health and social care provision. But later, when asked about how prevalent UNCRPD knowledge is among relevant stakeholders, he asserted that its impact is more restricted to the arena of policy.

NIP3: They certainly are aware of it. Policy staff are probably more aware of it than ambulance driver or what have you but hopefully through our role here we’re seeking to see the UNCRPD influence the general policies so to better operationalize UNCRPD considerations are standardized. I’d kind of have a different view about how we operationalize UNCRPD and the rights that are in it. Whether that means that everyone needs to know what UNCRPD is, or the guidelines, and the guidelines are informed by UNCRPD. It’s probably more of a realistic approach but certainly awareness of the UNCRPD in general would be broader throughout officialdom, people in policy.

NIP3 concluded with a broad overview on the implication of UNCRPD on society as a whole.

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587 Extract from interview with NIP4, 4 April 2016, transcript on file with researcher.
588 Extract from interview with NIP5, 4 April 2016, transcript on file with researcher.
589 Operational guidelines for daily health service staff which NIP3 considers should be reflective of UNCRPD principles, whether the staff using the guidelines are familiar with UNCRPD or not.
590 Extract from interview with NIP3, 30 March 2016, transcript on file with researcher.
NIP3: One thing to probably say is UNCRPD is all about mainstreaming disability considerations within society and I think here we have a long way to go to do that.\textsuperscript{591}

While there was some difference with the perceived impact of UNCRPD among the professionals, it has influenced the content of policies within NI. A publication of a review of health services in NI in 2011, Transforming Your Care\textsuperscript{592} was referenced by NIP1 as being central to successfully bringing about independent living in NI. This influence of UNCRPD is obvious from the report itself as it prioritises person centred planning, integrated services and incorporates Article 19’s advocating of the use of technology to facilitate persons with disabilities living independently and being included in their communities\textsuperscript{593}. However, NIP1 acknowledged that resources would not be guaranteed to accompany the policy.

\textit{Implementing the policy, Transforming Your Care, would be the big one. And trying to find resources to implement that. Particularly Transforming Your Care is very much about independent living.}\textsuperscript{594}

The other main national policy referenced by all the professional participants was the Northern Ireland Disability Strategy governs disability rights and services currently\textsuperscript{595}. Independent Living is identified as a primary theme in the Strategy and Strategic Priority 8 of the strategy is to increase choice and control for persons with disabilities over their lives\textsuperscript{596}. Article 19 UNCRPD is specifically referenced but the Strategy acknowledges the interconnectedness of all UNCRPD provisions to realise Article 19. The Strategy was extended to 2017 as the aims and objectives were not achieved within the original timeframe of three years from 2012-2015\textsuperscript{597}. However, the non-operation of the NI Assembly has resulted in no further commitments or drafting of a new strategy\textsuperscript{598}. It was highly criticized by participants in the professional category, but no reference was made to it by persons with lived experience. This could suggest that its impact remains largely in the policy and

\textsuperscript{591} Extract from interview with NIP3, 30 March 2016, transcript on file with researcher. ‘Transforming Your Care: A Review of Health and Social Care in Northern Ireland’, \texttt{<http://www.transformingyourcare.hscni.net/about/>}, accessed 4 April 2015.

\textsuperscript{592} Ibid at p. 46 and p.60.

\textsuperscript{593} Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.

\textsuperscript{594} All participants in the professional group made reference to the Disability Strategy as the primary current policy on disability issues.

\textsuperscript{595} Office of First Minister/Deputy First Minister, ‘A Strategy to improve the lives of persons with disabilities 2012-2015’.


\textsuperscript{597} Ibid
academic arenas. The lack of implementation, or any impetus or motivation to bring about implementation, as well as the weak rhetoric, was the primary cause for complaint.

NIP1: *In terms of other pieces of policies and legislation, the disability strategy would be the main one. All government departments are supposed to be looking towards. That has been really challenging, because I don’t know if you’ve seen the Disability Strategy. As a disability strategy it is very vague, it’s very grey. It’s supposed to be an implementation framework for the UNCRPD but it doesn’t mention all UNCRPD articles, there’s a lot of gaps in it, it doesn’t specify what actions need to be taken, no timeline, no funding allocated, so from that perspective there are serious issues.*

These concerns were echoed by NIP3: *The disability strategy is being very poorly enforced at the minute. We have concerns about it, it had proposed for an independent monitoring mechanism in it, a committee that had civil society, DPOs, ourselves involved in it. But it hasn’t really been formed off the ground so that’s a concern for us. We are emphasizing to OFM/DFM that they need to put this in place and now you have this change in departments, which is – where it’s going to go. So we’re watching that. But the disability strategy, we have concerns about how effectively it’s being implemented. The main mechanisms that you have for assessing effectiveness – annual report, the like of that, hasn’t really been put in place, and complied with, so that raises a concern for us with the disability strategy.*

NIP3 highlighted that while the disability strategy had been within the remit of the Office of the First Minister/Deputy First Minister, a high ranking office, recent changes to governance structures in NI resulted in uncertainty about the government department responsible for the disability strategy. This would jeopardise the effectiveness of the implementation of the strategy.

### 3.5.2 Post UNCRPD legislation and policy

Since 2012, efforts have been made to evaluate the effectiveness of disability services throughout NI. A 2014 report by Byrne et al.* is critical of the current Northern Ireland

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599 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.

600 Extract from interview with NIP3, 30 March 2016, transcript on file with researcher.

Disability Strategy as not addressing independent living as provided for under Article 19 of UNCRPD. As discussed in the previous section, this Strategy was originally intended to be implemented until 2015 but was extended until March 2017. The non-operation of the NI Executive since January 2017 has resulted in no further action on this strategy. Byrne et al’s report goes on to highlight the interconnectedness of Article 19 with a variety of other UNCRPD articles including Article 12 (equal recognition before the law), Article 20 (mobility), Article 29 (participation in public life) and Article 30 (participation in cultural life). These authors criticise the Department of Health and Social Development Services for failure to coordinate services, which they argue has prevented persons with disabilities from availing of the benefits which independent living can provide.

The previously discussed Mental Health (Northern Ireland) Order 1986 was updated by the Mental Capacity Act (Northern Ireland) 2016. This governs the assessment of capacity and treatment and deprivation of liberty of someone deemed to lack capacity. This does not automatically apply to persons with intellectual disabilities living independently, although they are at risk of having their capacity to make decisions to choose where and with whom to live assessed. Further, the provisions for deprivation of liberty and community residence requirements directly violate an individual’s right to exercise choice and control over where and with whom they live under Article 19 UNCRPD.

Consultation and representation of, and by, persons with disabilities in the development of legislation and policy in Northern Ireland was also a theme which the literature review did not reveal, but interviews with the professionals did.

NIP3: Just, you can have participation that gets you a photo, but it’s not necessarily participation. You know, a photo for a politician to put on their Facebook page, or what have

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605 Discussed at Section 3.3.7.


607 Section 30–34 of the Mental Capacity Act (Northern Ireland) 2016.
you, but it’s not necessarily them talking, engaging with a person with a disability where they are able to express their views. Meaningful participation.....Obviously with the Convention, the key line is ‘nothing about us without us.’

By contrast, NILE2 provided a positive example from his own experience of participation, representing persons with intellectual disabilities, with support from his advocacy organisation.

And are you part of an advocacy group?

NILE2: Em, well (disability service) is an advocacy group. And it’s good that you’ve asked that because I’ve actually done speeches on behalf of (disability service). Half for myself, and some about (disability service) and how it’s improved my life and all. And some of them things at schools like (local school) and universities like [regional university] and I’ve been on the radio talking about them.

So what sort of things would you have said in the speeches?

NILE2: Just talking about how my time has improved here and how my life has improved since I started. And I can’t remember the specific questions they asked but I remember saying in 2004 that society’s perception of learning disability was negative. And someone in here was listening and said you’ll get us into a lot of bother in here X, fair play to ya.

And do you think that has changed since 2004?

NILE2: Yeah, I’d say so, from my own experience.

NILE1 briefly referenced meeting a politician in a style of meeting that NIP3 may have been referring to as potentially lacking substance. However, both NILE1 and the support person were pleased with the interaction and found it engaging.

And when did you meet Gerry Adams then?

NILE1: I met him in here.

What was he doing?

NILE1: He was in talking to us. Gerry Adams came in here in under equality and with Martin Mc Guinness. He was doing a programme down about equality, and he came up here

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608 Extract from interview with NIP3, 30 March 2016, transcript on file with researcher.
609 Extract from interview with NILE2, 5 April 2016, transcript on file with researcher.
to visit the centre, see what was going on at the centre and find out what it’s about and what they’re doing here. And that’s why he came up here. But you were there was equality up and down the street, and he wanted to come here and meet the people, that was sitting in front of the audience. So fair play he took about an hour out to come here.\textsuperscript{610}

NILE1’s knowledge of the UNCRPD and advocacy was limited but her support person provided additional information on links between disability advocacy groups and other human rights campaigns.

Supporter: \textit{B and his friend from the (named human rights group) came down, he’s from Palestine.}  
NILE1: \textit{He told us.}  

Supporter: \textit{We had a scarf from Palestine, a photograph, that’s where it all came out of. Anything in terms of politics we’d do it, we’d be fairly quick on the ball. And it was X up in the (named human rights organisation) initiative. We actually had videos of people on the protests line in Palestine, d ‘ya mind wee [do you remember the person] X in the wheelchair?}\textsuperscript{611}

Other references to advocacy by participants in the lived experience group were not as focused on rights and often advocacy was incorporated into social activities.

NILE3: \textit{In the [advocacy] group. We did Zumba, like exercise.}\textsuperscript{612}

The nature of activities engaged in by advocacy groups and disability services informing persons with intellectual disabilities of their rights seems to be inconsistent from the reports of the participants. It ranged from exchanging experiences with disability activists in other countries associated with ethnic oppression to participation in exercise classes. So far this chapter has discussed the progress and developments of domestic initiatives to realise the right to independent living for adults with intellectual disabilities. The chapter will now consider the assessment of NI’s performance under Article 19 UNCRPD by international actors.
3.5.3 Civil society shadow reports

A ‘Jurisdictional Parallel Report’ on UNCRPD implementation in NI issued in July 2014 is critical of the Disability Strategy and its commitment to achieve independent living for persons with disabilities. This report notes that Regional and Quality Improvement Authority’s goal to ensure health and related services treatments are available in the community is not realised in practice due to the lack of availability of these services. The report describes how the manner in which residents have been moved from residential institutions to independent living accommodation has been badly coordinated with those most affected, and resulted in high levels of stress for persons with disabilities.

In July 2017 the four independent human rights and equality monitoring mechanisms in the UK – Equality and Human Rights Commission, Scottish Human Rights Commission, Northern Ireland Human Rights Commission and Equality Commission NI produced a collaborative report for consideration by the UNCRPD Committee. This report covers independent living and an adequate standard of living. The need to consider persons with disabilities in anti-poverty strategies was highlighted. The report recommended that NI should reopen the Independent Living Fund to new entrants as well as conduct research into the operation of self-directed services and direct payments on the lives of persons availing of these funding mechanisms. It further noted that care available to adults in the community must conform to Article 19 standards.

Disability Action prepared a shadow report for consideration by the Committee on the Rights of Persons with Disabilities. This report highlights the importance of independent living to ensure that the implementation of the Convention is meaningful in the lives of disabled people.

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614 Ibid at p.30.
616 Ibid at p 16.
617 Ibid at p 18.
618 Ibid at p 19.
people in Northern Ireland. While there are references to independent living in the National Disability Strategy, the usefulness of this is undermined due to a lack of legal definition of independent living in Northern Ireland and the failure to introduce specific policy actions to measure implementation of independent living initiatives as part of the Strategy620. The report notes that NI is lagging behind its UK counterparts in the provision of direct payments and self-directed services. This view was supported by NIP5621. The report also describes how reductions in eligibility for disability related services and the cumulative effect of such reductions in support can severely reduce independence for persons with intellectual disabilities. Disability Action suggest in this report that the UN Committee questions the State on the potential restoration of the Independent Living Fund and how the process of deinstitutionalisation for adults with intellectual disabilities resident in long stay hospitals will be implemented in Northern Ireland.

3.5.4 Committee on the Rights of Persons with Disabilities

3.5.4.i State Report

The United Kingdom of Great Britain and NI States party report to the Committee on the Rights of Persons with Disabilities was due in 2011 but was submitted in July 2013. The State report focused predominantly on initiatives in England, Scotland and Wales and this demonstrates the superior mechanisms for delivering independent living such as personalised budgets and a national Independent Living Strategy622. Provision of ‘residential homes’ for persons with particular disabilities, including intellectual disability is outlined as an option throughout the UK, and is one of which two participants of the research also availed623. In general, the report notes that these residential homes cater for four to eight persons, but acknowledges that larger homes are in operation624. The State highlights that residents exercise choice to live in this accommodation. The report included information regarding independent living in Northern Ireland, highlighting the ‘Supporting People’ programme, which provides advice and guidance for persons with disabilities to live independently625.

620 Ibid at p23.
621 Extract from interview with NIP5, 4 April 2016, transcript on file with researcher. Discussed at Section 3.4.5.
622 Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by States parties under article 35 of the Convention, Initial reports of States parties due in 2011, United Kingdom of Great Britain and Northern Ireland, paras 174-179.
623 Ibid at para 183.
624 Ibid at para 183. The accounts of NILE1 and NILE3 suggested that their accommodations are considered to be larger group homes. Transcripts on file with researcher.
625 Ibid paras 185-186.
The Supporting People programme has been in effect since 2003 with the most recent version of the Strategy spanning 2012-2015. The Strategy acknowledges the non fulfilment of deinstitutionalisation and provides detail on the type of accommodations provided through the Housing Executive for persons with ‘learning disabilities’. These vary, as reflected in the lived experience participants living arrangements, accommodating up to 25 people. This policy was not referenced by any participant in the qualitative research.

3.4.4.ii Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention, Report of the Committee 6 October 2016.

Prompted by information on the adverse impacts of social welfare reform in the UK on the enjoyment of the right to live independently, the Committee on the Rights of Persons with Disabilities conducted an inquiry to examine legislation and policies bringing about these violations. Its findings demonstrate that the reforms have hampered the progress of deinstitutionalisation across the UK and resulted in an increased reliance on family or institutionalisation for accommodation was. This finding resonates with the experiences of the interview participants in the qualitative research conducted for this thesis. In its inquiry report, the Committee also criticises non-acceptance of new applicants to the Independent Living Fund in Northern Ireland.

3.4.4.iii UNCRPD Committee examination

The UK was due to be questioned by the Committee on the Rights of Persons with Disabilities in 2015, but the dialogue was delayed until August 2017. On 3 October 2017 the Committee on the Rights of Persons with Disabilities released Concluding Observations on the United Kingdom of Great Britain and Northern Ireland. From the outset, the Committee commends the inclusion of persons with disabilities in the formation of policies at

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627 Ibid at p. 27-28.
628 Committee on the Rights of Persons with Disabilities, Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention, Report of the Committee 6 October 2016, para 96-98.
629 Ibid para 99.
631 Committee on the Rights of Persons with Disabilities, Concluding observations on the initial report of the United Kingdom of Great Britain and Northern Ireland.
a national level. It is critical of the lack of legislation recognising the right to live independently and participate in the community in the UK, including Northern Ireland. These Observations identify the negative impact of policies relating to housing and in particular reductions in budgets for independent living for persons with disabilities. The transfer of responsibility for independent living to the devolved governments without sufficient ring-fencing of funds is noted. The rationalisation of cost by local authorities for the continued institutionalisation of persons who cannot afford their own personalised assistive services, compounded by the lack of availability of personal assistance and accessible public facilities in a non-discriminatory manner is criticised. The Committee recommends the consultation of persons with disabilities to assess the impact of policies. Further, it recommends the provision of adequate earmarked funding for independent living and community participation to local authorities within devolved governments. The Committee recommends that the state must devise a deinstitutionalisation plan which encompasses education, transport, childcare and employment among others and this must be accompanied by sufficient resources to ensure no disparity of enjoyment of independent living in urban and rural areas. NI would benefit significantly from this last observation in respect of Article 19.

The impact in NI of the failure to fully consider inclusion and living conditions of persons with disabilities was highlighted as a principal area of concern for the Committee. The Committee recommended the collection of data to inform a measurable strategy to improve living conditions for persons with disabilities in NI. The Committee recognised the hiatus of the Assembly but encouraged the State to incorporate the UK Independent Mechanism’s recommendations to reform disability law and to ensure protection from direct and indirect disability discrimination. The Committee also suggested that the additional costs associated with disability should be reflected in policies determining income levels and the state should repeal recent alterations to the Personal Independence Payments and ensure social welfare payments are in line with a human rights model of disability.

This has been the most recent international commentary in relation to the realisation of Article 19 UNCRPD for adults with intellectual disabilities in Northern Ireland.

632 Ibid paras 7-8.
633 Ibid at para 45.
634 Ibid at para 45.
635 Ibid at para 8.
636 Ibid at para 17.
637 Ibid at para 58.
3.6 Conclusion

The progression of disability legislation and services in NI has been delayed compared to that of England, Scotland and Wales. Morgan\textsuperscript{638} is extremely critical of the lack of action among persons with disabilities themselves. He laments a lack of disability culture in either the North or South of Ireland\textsuperscript{639}. This view is supported by the organisation ‘Disability Rights in Ireland’, which asserts that Catholic minority rights were the dominating issues of the social movement in NI\textsuperscript{640}, and that these eclipsed other equality issues. Morgan highlights the positive developments for persons with disabilities in NI by virtue of the affiliation with the United Kingdom systems. The behind the scenes efforts of activists in England which I discussed in Chapter 2\textsuperscript{641} no doubt paved the way for the legislation in NI by providing positive examples of independent living programmes which could be implemented practically and in a meaningful manner.

It was clear during the interviews that the desk based research had identified the majority of laws and policies applicable in NI. Participants made some references to English policies that are not applicable in NI and provided detailed accounts of involvement in law making process during Direct Rule by the UK government. Hate crime targeted at people with intellectual disabilities or litigation had not featured in the desk based literature review for NI but two cases were referred to across three interviews. The interviews were particularly useful in providing information on the internal organisation of disability services and the ‘behind the scenes’ work on policy making and the challenges associated with inclusion of persons with intellectual disabilities.

No references were made by professionals to the five year planning policies\textsuperscript{642} of disability services and from the descriptions of their experiences, especially NIP4 and NIP2, their work revolved more around a flexible approach to meeting the requirements of their service-users and staff. The fact that National Disability Strategy, the five year departmental planning

\textsuperscript{638} Belfast born, Morgan was prompted to engage in disability activism after being refused a lecturing position as his disability was considered to be distracting to students. Socialist Democracy, ‘Michael Morgan An Appreciation, 29 April 2007’, <http://www.socialistdemocracy.org/News&AnalysisIreland/News&AnalysisIreMorganAnAppreciation.html>, accessed 14 August 2014.
\textsuperscript{641} Section 2.3.
\textsuperscript{642} 1987-1992 Regional Strategy for Health and Personal Social Services and Health and Wellbeing into the next Millennium, the Regional Strategy for Health and Social Wellbeing 1997-2002’
policies and Transforming Your Care were made at the high levels of the Department of Health could indicate a lack of consultation with the people the policies purported to serve. There was no indication that these policies were ignored, rather there was a necessity for staff on the ground to be flexible and responsive to the unique situation of the Troubles which was not addressed in government guidelines or policies.

The conflict and peace process seemed to have impacted the participants in a similar way to the impact on the general population. Not everyone was directly impacted through death or injury but to some extent everyone’s lives were impacted through disruption to daily activities. Overall participants with lived experience were given limited information about the conflict by family members or staff in disability service providers, although this could regarded be a protective measure due to the secrecy and covert nature of conflict-related activities of the Troubles.

In terms of Article 19 of the UNCRPD the accounts of the participants were varied. Two of the participants are currently being denied the right to live independently – their residential situation lacks choice and control over where and with whom they live – but both report satisfaction with their current arrangements. The other three participants are heavily reliant on family members, mixed with state and voluntary services, for support. However all participants did mention being able to access a variety of services, being engaged through voluntary work or educational initiatives and socializing. All of these are activities which come within the scope of Article 19.

This chapter has provided an overview of the impact of legislation and policies related to disability services and human rights in Northern Ireland and experiences of the conflict and peace process over the lifetime of persons with intellectual disabilities who were entering adulthood at the start of the Troubles.
Chapter 4: Bosnia Herzegovina

‘If the international community is not ready to defend the principles which it itself has proclaimed as its foundations, let it say so openly, both to the people of Bosnia and to the people of the world. Let it proclaim a new code of behaviour in which force will be the first and last argument.’

— Alija Izetbegović
4.1 Introduction

This chapter provides an overview of legislation and policies affecting the right of persons with intellectual disabilities to live independently in Bosnia Herzegovina (BiH) from the 1960s onward so as to be comparable with the research undertaken for Northern Ireland. This period of time has been one of considerable change in Bosnia Herzegovina. These include a transition from the Soviet Federal Republic of Yugoslavia (SFRY) to an independent democracy and a domestic ethno-nationalist conflict. The conflict received international attention for the Siege of Sarajevo and violence amounting to genocide. American diplomacy assisted brokering peace with the Dayton Peace Accords, international monetary investment was made available and ratification of the UNCRPD occurred in 2010. Most recently BiH is a currently a candidate for European Union membership. The chapter is divided into four broad sections – 1) Pre conflict 1960s – 1980s, 2) During conflict 1992-1995, 3) Post conflict 1995 - 2010 and 4) Post UNCRPD ratification 2010 - present. Each section is introduced with information on the main events relating to the political landscape and the conflict. The chapter is divided so as to clearly address the research questions set out in chapter 1643.

The first section addresses Research Question 1 – ‘How were the lives of persons with intellectual disabilities impacted by legislative and policy measures governing disability services supporting independent living in years immediately preceding the conflict?’ This section discusses legislation and policies relating to the health and social services in operation in SFRY before the conflict. This will focus on the 1960s to 1980s.

The second section examines Research Question 2 – ‘How were intellectual disability services impacted by the conflict and what were the experiences of persons with intellectual disabilities during the conflict in BiH?’ The conflict in BiH was much shorter but the nature of the conflict was extremely violent and involved armed combat and genocide. The impact of the conflict on the organisation and delivery of disability services and accounts from both interview groups – lived experience and professionals- will be incorporated to the literature.

The third addresses Research Question 3 – ‘To what extent were the rights of persons with intellectual disabilities to live independently considered in post-conflict societies during state re-building?’ The impact of the Dayton Peace Accords from 1995 to 2010 on independent living legislation and policies and the experiences of the participants in the post conflict years will highlight the consideration of disability in BiH as peace resumed.

643 Discussed at Section 1.2.
The final section addresses Research Question 4 – ‘To what extent has BiH complied with their obligations under Article 19 UNCRPD - to facilitate independent living and inclusion in the community for persons with intellectual disabilities?’ The research will consider the impact of the ratification of the UNCRPD since 2010, the associated legislation and policies and the current independent living experiences of adults with intellectual disabilities in BiH.

Terminology specific to this chapter refers to the primary ethnic groups involved in the conflict. The term ‘Bosniak’ refers to people identifying as Bosnian Muslims. Bosnian Serb refers to people with allegiance to the Serbian nationality within BiH. Bosnian Croat refers to people with allegiance to Croatia who reside within BiH. States and entities referenced in this chapter include the Socialist Federal Republic of Yugoslavia (SFRY), the Federation of Bosnia Herzegovina (FBiH), Brčko District and the Republica Srpska – the Serb Republic. The SFRY was the collection of states in the Balkan region under the control of Communist dictator Tito from 1944 until his death in 1980. FBiH, Brčko District and Republica Srpska are the three new entities created within BiH after the conflict. FBiH refers to the entity as opposed to the nation state of BiH.

Fieldwork and desk-based research in this jurisdiction was approached with much less familiarity with the conflict and the state than with NI. Desk-based research provided details on the demographics of the state, nature of the conflict and the text of multiple legislative and policy provisions. However, fieldwork facilitated a better understanding of how the state governance structures operate. A brief profile of the state is provided below.

### 4.1.1 Bosnia Herzegovina country profile

Located in south east of the European Continent, BiH has a population of 3,531,159 according to the 2013 census. This population is spread across urban and rural regions of a state heavily shaped by the period of conflict being examined in this chapter. The predominant ethnicities of the population are reflected in the tri-partite presidency, one

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644 This term became officially in use from the mid 1990s but as the majority of the literature referenced dates from after this period it has been commonly used to denote the Bosnian Muslim ethnicity. Dimitrova, B, Bosniak of Muslim? Dilemma of one nation with two names’, South Eastern European Politics (2001) Vol. 2, No. 2, 97 <http://www.seep.ceu.hu/issue22/dimitrovova.pdf>, accessed 14 January 2018.


member elected by each of the Bosniak, Serbian and Croatian constituent peoples. Territorial division of the state in line with perceived ethnic populations has created a population spread across three entities – FBiH (2,219,220), Republica Spark (1,228,4230) and the Brčko District (83,516). These entities are further divided into smaller regions, referred to as cantons and municipalities. These local governance structures have authority over legislation, policies and resource allocation related to social issues, under which services with disabilities is provided. The total population of persons with disabilities in 2013 was 294,058. It is not possible to determine the population of persons with intellectual disabilities as the categories listed are not adequately defined.

BiH is currently a candidate for EU membership. Its application for membership was formally accepted in 2016 and BiH continues to undertake actions to integrate with the EU policies across areas over which the EU has a mandate – finance, trade, agriculture, education and human rights among others.

There is no unified system of social protection in BiH. The Ministry for Human Rights and Refugees is the national organ responsible for the implementation of international instruments through local social protection policies. At the FBiH level, the Federal Ministry of Labour and Social Policy is responsible for a significant mandate associated with

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650 Ibid at p. 116

651 Ibid. The categories for types of disabilities are: ‘Seeing, even with the use of glasses’, ‘Hearing, even with the use of hearing aids’, ‘Walking of going upstairs’, ‘Remembering or concentrating’, ‘Dressing and bathing’, ‘Communication, understanding other people’. Persons with intellectual disabilities could identify with any, all or none of the above categories.


655 Ibid
disability. These include social welfare, pensions, employment, disability insurance and compliance with international human rights provisions. This is a very wide mandate with multiple staff allocated to each of the sub-sectors. Each canton then devises priority areas and allocates finances and resources which are delivered by Centres for Social Work. These are community based and provide multi-disciplinary social services staff. Their remit is the prevention and monitoring of social problems, direct provision of social services and health initiatives. The statistics on people relying on social protection in BiH increased steadily between 2007 and 2014 which is in line with the international economic recession. However, these increases were predominantly the recipients of cash benefits with no indication of increase of investment in actual social service funding. Further, the Centres for Social Work are described as being under resourced, staff not fully equipped and trained for their workloads and with no organisational impetus to improve standards or systems. In the Republica Srpska the Ministry of Health and Social Welfare delivers social protection while in the Brčko District this falls under the remit of the Department of Health.

The conflict has had a major impact on the current system of health and social services, upon which persons with intellectual disabilities are reliant for basic resources and supports. The resulting complex administrative systems in BiH have not embraced an ethos of independent living in their delivery of services at a national level. Suvad Zahirovic, a visually impaired Bosnian disability rights advocate, recounts the unfortunate timing of the conflict in BiH, occurring when Centres for Independent Living became popular throughout Europe. He asserts that the arrival of international NGOs in the aftermath of the conflict was the first

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657 Ibid
662 Ibid
663 Ibid
exposure Bosnians with disabilities had to information on the global disability rights
movements. This chapter will ascertain whether this statement applied to adults with
intellectual disabilities also.

4.2 Section 1: Pre Conflict situation (1960s-1980s)
BiH, like NI, has been directly detrimentally impacted upon by conflict over the last century.
The city of Sarajevo in particular has played a hugely important role in international
conflict. The assassination of Archduke Franz Ferdinand of Austria is renowned as setting
off the chain of events leading to the World War I. This event has arguably contributed to
the majority of armed conflicts since the re-drawing of state lines, mass movement of
populations and the alliances of powerful Western states with Eastern states rich in natural
resources.

In the 1930s and 1940s, BiH experienced political instability and violence due to the rise of
Croat nationalist extremists (supported by Nazi forces) who were perpetrators of violence in
line with Holocaust policies. In the wake of World War II, the Communist dictator, Tito,
was successful in administering a constitutional structure of governance which satisfied the
various national identities within the then Socialist Federal Republic of Yugoslavia
(SFRY), albeit through the abolition of free speech and suppression of criticism of
government. While maintaining independence from the Soviet State, Tito’s nationalisation
of industry conformed to Communist practice but also introduced a social welfare system
which brought about social protection for the elderly, persons with disabilities and maternity
leave. Archer acknowledges the emphasis in the literature on the economic system within
the SFRY during this period, but highlights that significant social inequality was experienced

by the population at this time\textsuperscript{672}. Jansen’s research on everyday life in the SFRY recounts that citizens were satisfied once basic employment and accommodation needs were met\textsuperscript{673} and that residents of SFRY experienced a more moderate form of socialism than that implemented in other states\textsuperscript{674}.

International human rights standards were not alien to the SFRY, which was an original member of the United Nations since 1945\textsuperscript{675}. The United Nations Treaty Collections provide details of the multiple agreements which SFRY was party to, with topics varying from bank regulation to empowerment of the World Health Organisation\textsuperscript{676}. Initiatives existed within the SFRY to promote activity for persons with physical disabilities, for example, through participation in the Paralympic Games, which had been originally established for rehabilitation of World War II veterans\textsuperscript{677}. This is in contrast to their Communist neighbour and influencer, the Union of Soviet Socialist Republics (USSR). A government official reportedly told a member of the media that USSR would not participate in the 1980 Paralympic games as there were ‘no invalids’ in the USSR\textsuperscript{678}. SFRY was a party to a number of UN human rights conventions, including the ICCPR\textsuperscript{679}, ICESCR\textsuperscript{680} and ICERD\textsuperscript{681} from 1966, while UNCEDAW was ratified in 1979\textsuperscript{682}, UNCAT in 1984\textsuperscript{683} and UNCRC in 1989\textsuperscript{684}.


4.2.1 Domestic Legislation applicable to persons with disabilities

The Constitution of the SFRY underwent three revisions in the aftermath of World War II until the final version in 1974\(^{685}\). To facilitate comparison with research conducted on NI from the 1960s onward, this section will analyse the provisions for persons with disabilities in the 1963 Constitution as well as the version in place before the dissolution of the SFRY.

The 1963 Constitution is a strongly socialist document with the social community taking responsibility in all aspects of life. Article 33 outlines the equality of all citizens but disability is not listed as a ground where discrimination is prohibited. Discrimination is however prohibited on the basis of an individual’s education level and social status, and persons with intellectual disabilities often experience discrimination on these grounds. Article 36 refers to employment and conditions of work that shall be created favourably to the capacities of those less well placed to work. It creates a distinct difference between those incapable of work and those who refuse to work. People who are fit to work but do not choose to do so will not be granted the rights and social protection connected to employment. Article 37 provides for special protection in employment conditions for ‘youth, women and disabled persons’\(^{686}\). Article 57 refers to the role of the social community in the provision of ‘special protection’\(^{687}\) for those unable to provide for themselves or safeguard their own rights. This could encompass persons with intellectual disability. The most specific references to disability relate to wounded war veterans, also contained within Article 57.

\(^{687}\) Ibid
Amendments to the Constitution subsequently increased the autonomy afforded to the provinces, which would eventually become independent states. The 1968 Constitutional amendments focused on the power of provinces to create their own constitutional laws and supreme courts; and recognized the diversity of populations through a change in official terminology from ‘national minority’ to ‘ethnic groups’. Further amendments in 1971 related primarily to employment and labour rights which did not specifically relate to persons with disabilities.

A complete copy of the 1974 Constitution is not available in English online but there are indications that the crux of the provisions remained similar to the previous version from 1968. The majority of changes related to governance and Bell describes the problematic lack of direction within this Constitution for dissolution of the Federation, if it were to occur.

A 1981 census of the SFRY indicates a total population of 22,418,331. Within this, the population of BiH was 4,125,000. Muslims comprised the largest group in 1981 in BiH with the census indicating a 39.52% majority, followed by Serbs with 32.02% and Croats with 18.38%. Ethnic majorities were dispersed geographically. Tabeau and Bijack indicate that this ethnic diversity within BiH contributed to the complexity of the separation from the SFRY.

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689 Ibid
690 Ibid
4.2.2 Health Services within SFRY

Rassell and Larskaia-Smirnova\textsuperscript{699} note the relatively recent exposure of the experiences of persons with disabilities to academic researchers in Eastern Europe. Prior to this, the focus of health-related research in the region remained on the experiences of medical practitioners and mainstream human rights activists. Magajlic and Rasadagic similarly report difficulty in obtaining any reliable data on socio-economic indicators related to the general population until 2000, and in the case of health and disability indicators, no data is available before 2004\textsuperscript{700}. As a result of this lack of data on disability in the jurisdiction, accounts from neighbouring states act as illustrative of the approach in SFRY and BiH at the outset of the conflict. Phillips describes social policy for persons with physical disabilities in the USSR from the 18th century onward but provided useful information on the policies from World War II onward\textsuperscript{701}. Phillips notes that during the 1940s the rehabilitation of war veterans with disabilities to engage in the workforce was a high priority in the USSR\textsuperscript{702}. This is reinforced in a World Bank commissioned study by Tobis who chronicled the transition from institutions to community based services in the region\textsuperscript{703}. However, in former SFRY and USSR states institutionalisation of persons with intellectual disabilities, children and elderly continues\textsuperscript{704}. This is due to pressure from the organisations providing institutions, a social welfare and legislative structure which is incapable of addressing the needs of vulnerable members of society, finance packages which prefer institutions and the demand from the public for the state to continue to provide these services as the economies of the regions have deteriorated\textsuperscript{705}. This chapter will now provide more detail on the system encountered by persons with intellectual disabilities from initial diagnosis to institutions which has been collected from literature and contributions from the lived experience participants.

\textsuperscript{702} Ibid
\textsuperscript{704} Ibid
\textsuperscript{705} Ibid
4.2.3 Disability diagnoses

The OECD provides only a brief reference to children with disabilities being ‘screened’ in pre-conflict BiH but there are no details to the nature of disabilities being screened\textsuperscript{706}. There is acknowledgement of the segregation of children with disabilities within institutions and that conditions of these institutions were poor\textsuperscript{707}.

When preparing to undertake this qualitative research I had anticipated that participants’ accounts of receiving a diagnosis of disability and having interventions – education or other supports – put in place would be relatively straightforward. It was clear from very early on in each interview that there was a distinct lack of consistency or regulation of a system for intellectual disability diagnosis and interventions for the participants in their youth in the SFRY. Only one participant was diagnosed as having a disability in their youth and this was due to her having a more evident intellectual disability, Down syndrome\textsuperscript{708}.

For the remaining participants, the disability was not diagnosed until adulthood\textsuperscript{709}. The literature on Northern Ireland disability policies had indicated well established systems through health and education for the diagnosis of intellectual disabilities. I had not found any references to such a system of diagnosis in BiH. To address this gap in knowledge I diverged slightly from the questions asked of the NI lived experience participants. The table below shows the experiences of these participants in receiving a disability diagnosis.

\textit{Table 9. Disability diagnosis BiH.}

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Childhood</th>
<th>Adulthood</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>3\textsuperscript{710}</td>
</tr>
<tr>
<td>Female</td>
<td>1</td>
<td>1\textsuperscript{711}</td>
</tr>
</tbody>
</table>


\textsuperscript{707} \textit{Ibid}

\textsuperscript{708} BIHLE4 has Down syndrome.

\textsuperscript{709} Four participants cited from 2000 onwards as being when they received an official diagnosis of their disability.

\textsuperscript{710} The disability of one of these participants was suspected during childhood. Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher. All three of these diagnosis were received while the participants were accessing post-conflict health services.
4.2.4 Social welfare

One element that appears to have influenced more recent Bosnian disability policy is the USSR’s welfare system which established categories for income support based on the origin and nature of the individual’s disability. Phillips translates a Russian description of the categories, explaining that priority was given to those injured in military service, depending on which armed activity the individual engaged in. Persons who acquired disability at the workplace or due to the actions of another person are next in the hierarchy, while persons with disabilities from birth, under which persons with intellectual disabilities would usually be categorized, are the lowest tier of the hierarchy\textsuperscript{712}. This categorisation was based on the perceived potential of different persons with disabilities to contribute to society, an extremely important element of socialist societies\textsuperscript{713}. Those disabled during military service or at work received higher benefits in SFRY, as praise for their contribution to society\textsuperscript{714}. This demarcation of disability categories has resulted in differences in treatment by the state depending on individual circumstances. The welfare system in SFRY therefore did not acknowledge society as creating a disabling environment, instead it focused on the cause of the disability at an individual level, stifling recognition of persons with disabilities as equal citizens\textsuperscript{715}. Initiatives to encourage participation in the workforce were individualized and sought to restore perceived absence of ability\textsuperscript{716}.

A significant element of the social welfare system in the USSR and SFRY were state-run institutions for persons requiring care not available in the community – orphans, elderly and persons with disabilities. Arula explains that in the SFRY children with intellectual disabilities were placed in institutions for their childhood, after which legislation provided that the local municipality was obliged to ensure employment and accommodation for

\textsuperscript{711} The disability was suspected during childhood. Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher.
them\textsuperscript{717}. Sutton provides a similar overview of the reliance of social protection institutions which were regarded as beneficial services provided by the state for vulnerable citizens in the USSR\textsuperscript{718}. Segregated education was provided but children with intellectual disabilities were often considered uneducable in the USSR so persons with intellectual disabilities were further excluded within already segregated settings\textsuperscript{719}. No literature is available to indicate whether this attitude extended to education of persons with intellectual disabilities in SFRY but the qualitative research indicated that segregated education was of a basic literacy and numeracy level\textsuperscript{720}. This chapter will now discuss the nature of institutions in operation in SFRY in the period before the Bosnian conflict.

4.2.5 Institutions for persons with disabilities

Family Matters provides an overview of the historical rationale behind the institutional nature of services for persons with disabilities in the Central and Eastern European Region\textsuperscript{721}. This report explains that Communism brought about a prioritization of state-provided institutional care over parental care of children with disabilities, with the aim to alleviate the pressures on families experiencing poverty after World War II. They also draw a connection between children placed within these institutions and the occurrence of symptoms associated currently with intellectual disabilities – including reduced cognitive and social ability\textsuperscript{722}.

Jansen, Brkovic and Celebicic indicate that residential institutions for persons with disabilities were in place from the 1950s in the SFRY but there were discrepancies in how the institutions were organised and services delivered\textsuperscript{723}. Families who provided support to children, the elderly, persons with disabilities and so-called ‘criminal youths’\textsuperscript{724} before the

\textsuperscript{717} Arula, B., Children without parental care, Children and Youth Issues In human rights context in Bosnia and Herzegovina, at p.218
\textsuperscript{719} Ibid
\textsuperscript{720} Extracts from interviews with BIHLE5, 10 May 2016, and BIHLE5, 3 November 2016, transcripts on file with researcher. These two participants availed of segregated education and said they received basic education and also referenced practical skills training such as knitting and slipper production as older children.
\textsuperscript{721} Every Child, ‘Family Matters: A study of institutional childcare in Central and Eastern Europe and Former Soviet Union’, <http://p-ced.com/reference/Family_Matters_summary.pdf> accessed 3 June 2014. Bosnia and Herzegovina are reported to have such limited data available that it is excluded from this report.
\textsuperscript{722} Ibid at p.13.
\textsuperscript{723} Jansen, S., Brković, C., and Celebecic, V., Negotiating Social Relations in Bosnia and Herzegovina: Semiperipheral Entanglements. Routledge (2017)
\textsuperscript{724} Ibid at p. 104.
introduction of these institutions attempted to continue to fulfil this role but there was coercion from social workers to parents to surrender children with disabilities to the institutions. As the Literature Review indicated, this was a common occurrence internationally as the options for disability services to families were very limited. Their research indicates that the system of segregation to social institutions for persons with disabilities in the SFRY, including persons with intellectual disabilities, resulted in the invisibility of these groups. The standards of care in social institutions were considered to be of low quality and these institutions were ineffectively managed with a strong focus on the medical model of disability. Stambolieva highlighted the inequalities of standards in social institutions among the republics of the SFRY, as considerable investment was required at local level and this was dependent on the prosperity of the locality.

Beyond childhood, the emphasis was on vocational education for persons with disabilities, as this was deemed more appropriate than education with a strong academic focus. This was due to the perceived inability of persons with intellectual disabilities to participate in work that required advanced university education. Efforts to lobby for disability rights and to publicise rights violations were severely sanctioned by USSR intelligence and security forces during the 1980s which potentially had a chilling effect throughout the region on similar advocacy activities.

For the participants, unless the disability was evident from birth, there was no system through health or education services to recognize additional support needs. Apart from BIHLE4 the participants’ families did not seek to pursue diagnoses for their children which could be related to stigma or fears of separation from their children.

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725 Ibid at p. 105.
726 Ibid at p. 106.
729 OECD provided example of visually impaired persons being trained to work on switchboards. Education Policies for Students at Risk and those with Disabilities in South Eastern Europe Bosnia-Herzegovina, Bulgaria, Croatia, Kosovo, FYR of Macedonia, Moldova, Montenegro, Romania and Serbia: Bosnia-Herzegovina, Bulgaria, Croatia, Kosovo, FYR of Macedonia, Moldova, Montenegro, Romania and Serbia, OECD Publishing, 2006 at p. 18.
While there is no specific literature available in English on intellectual disability services in BiH, it can be ascertained from the desk based research that services for persons with intellectual disabilities in the region during the late 20th century provided by the state shared the characteristics of segregation and institutionalisation experienced internationally. The accounts from the qualitative research outlining the nature of disability service provision in BiH before the war addresses the gaps in the literature on this topic.

The literature discussed so far correlates to the periods during which participants with lived experience in my qualitative research were in their childhood and early adulthood from the late 19790s and during the 1980s. The discussion will now turn to consider the actual experiences of the participants in their childhoods before the war.

4.2.3 Living Arrangements

Table 10 Living Arrangements BiH.

<table>
<thead>
<tr>
<th>Gender</th>
<th>Accommodation</th>
<th>Family home</th>
<th>Institution</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>0</td>
<td></td>
</tr>
</tbody>
</table>

Although Tobis and Phillips suggests institutionalisation in the region was a common experience for persons with disabilities from childhood, the absence of a diagnosis for the majority of the participants in this research may have contributed to them avoiding institutionalisation in their childhoods. Living with family members was a feature of

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733 Participants with lived experiences are identified as BIHLE1-5. Participants in the professional group are identified as BHP1-5.
childhoods for all participants, although for one participant this was only temporary due to familial breakdown. BIHLE2 indicated that he was not aware of institutions during his childhood. This suggested to me that there was no consideration by his family of availing of an institution for his care.

BIHLE4’s living situation has remained constant throughout her life and is based in an urban area. Reference is made by BIHLE4 to her sibling and his family through marriage. Having such positive relations with siblings, in-laws, nieces and nephews during adulthood indicated to me during the interview that overall her childhood family relationships were pleasant, especially in comparison to the other participants’ experiences.

BIHLE3 described the rural conditions with her immediate family during her childhood as being of low standard.

BIHLE3: She is comparing her previous life to her existence now, her current status and how she was living in poor conditions. Having bad nutrition. She didn't have a room of her own.

BIHLE1 spent most of his childhood living with his maternal grandmother following his parents’ divorce. However, he was conscious that not living with his parents marked him out as different to his classmates. BIHLE5 had the most limited experience of family living arrangements as a child. Immediate family, extended family and institutions all played a role in his childhood. Religion and ethnicity was not reported as a factor for tension in the institution in which he resided. However, he indicated that there was a lack of personal space and choice in the institution.

BIHLE5: They put him in that institution because they don’t have any other choice. Because of his behaviour, because they don’t have another institution in option. So in that institution he doesn’t have many free time to go to the town. He had some money and he went to summer, to the sea couple of times. He was satisfied in that institution. It was better in that institution for children without parents than the institution he went to after the war.

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736 Extract from interview with BIHLE2, 9 May 2016, transcript on file with researcher.
737 Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher.
738 Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher.
739 Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher.
740 Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher.
Later in the conversation BIHLE5 referred to staff: *There was a little bit of authority. But he said that he is satisfied with them but he said they need to have authority. So...they told them, staff told them in the institution ‘from here you will go like a proper man’*. They learned us a little bit of life and everything.

The participants with disabilities in this research describe a wide range of childhood living situations, details of which had not been accounted for in the literature. There was no engagement with social care professionals in their childhood or early life by four of the five participants, although one participant had experience of institutionalisation in childhood.

Three participants representing professionals working in disability services or on disability policy also provided information on their perceptions of how disability services were delivered prior to the conflict, although the proximity to the services varied widely. Sectarianism and ethnic discrimination did not seem to be a feature of disability services before the war, according to these participants’ knowledge. BIHP5 relayed her knowledge of a friend’s family situation accessing disability services before the conflict.

**BIHP5:** *There were none* [supports for families of persons with intellectual disabilities]. *A friend’s* brother has been there his entire life. That tells you he was given away as a baby just because the family received no support whatsoever to keep him at home. And they were, the only option that they were given was to surrender him to the home. And this is what they did. They are still visiting him daily and everything but it’s... that was the only option. And it still basically is because they will receive no support. And now their mother is [aged] 60 something so she wouldn't be to take care of him herself.

**Do you think families were encouraged to put people into institutions?**

**BIHP5:** *I know they were.*

BIHP4 provided a more nuanced account of disability services that existed before the war in Bosnia which reflected accounts by BIHP2 and BIHP5.

**BIHP4:** *So in pre-war Bosnia Herzegovina people with disabilities, including persons with intellectual disability were mostly placed in close type institutions if they didn't have any*

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741 Ibid
742 Due to time restrictions BIHP1 only made a brief reference to pre-war services and BIHP2 was not questioned about it at all.
743 Extract from interview with BIHP5, 3 November 2016, transcript on file with researcher
other kinds of support, a family member who was willing to take care of them or who could take care of them both financially and professionally. But if they did have family members then they would live with their families who would take care of them. There were no communities such as the ones we have today where [they] could be taken care of. The government provided financial support – money, fees and pensions. However that was only on the financial basis. There was no proper services in terms of psycho-social support, personal assistance, inclusion in the community.\(^{744}\)

BIHP3 worked in the administration of disability service delivery and had a unique perspective. She referred to the regimented nature of disability policies prior to the conflict as being positive in terms of organizing disability services such as rehabilitation.\(^{745}\) She described how buildings were made accessible to accommodate persons with disabilities in local communities before the conflict. However, she conceded towards the end of the discussion that this approach was not of a standard that would be approved of today. The inconsistency of BIHP3’s account with the accounts of the other participants does resonate with Jansen, Brkovic and Cereberic’s assertion that disability services were not implemented in a manner consistent with how they were planned.\(^{746}\)

The evidence of the lack of consistent state services links with another theme emerging from the qualitative research, the importance of family support, which is discussed in the following section.

### 4.2.4 Family support

Table 11. Family Support BiH.

<table>
<thead>
<tr>
<th>Supports</th>
<th>Gender</th>
<th>Family</th>
<th>Institutionalisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>2</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>2</td>
<td>0</td>
<td></td>
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</tbody>
</table>

\(^{744}\) Extract from interview with BIHP4, 10 May 2016, transcript on file with researcher.
\(^{745}\) Extract from interview with BIHP3, 6 May 2016, transcript on file with researcher.
References to family support during childhood and into adulthood were made by all BiH lived experience participants\textsuperscript{747}. As could be expected, socio-economic factors contributed to the capacity of each participant’s family to provide supports. BIHLE4 described the early interventions she received in her youth, including availing of therapeutic services in a neighbouring jurisdiction, obtained at large expense to her family. The participant placed significant emphasis on the support her mother has given her and the benefits of the support.

**BIHLE4:** *That included physical therapy because she wasn't even able to hold a pen by herself. Her mother practiced a lot with her as well. She had brittle bones. Her mother has a brother in Germany so he financed a lot of her therapy. He financed these expensive injections she received. She commuted a lot between Slovenia and Sarajevo to get her treatment at an early age. She also underwent physical therapy in Slovenia, physical therapy on her legs and her hands so she could use [them]. She couldn't write or anything. She thanks God that she has her mother.*\textsuperscript{748}

BIHLE3 indicated that the religious and conservative attitudes towards the role of girls and women in the rural area in which she grew up, combined with attitudes towards disability, and resulted in negative experiences for the participant\textsuperscript{749}. While the contributions from the professional group had indicated that there was no religious segregation in the delivery of disability services, individuals who did not engage with the state for disability services could still have been subjected to religious restrictions on their freedom of movement to the extent that their family observed various practices, beliefs and customs.

BIHLE5 was able to continue his contact with family during the time he was placed in an orphanage\textsuperscript{750}. This seemed to take the form of visits during weekends and school holidays. BIHLE2 had indicated at the beginning of the interview that a close family relative had died recently and his demeanour suggested to me that pressing the topic of family experiences would not be appropriate. BIHLE1’s family support came from his grandmother, as is referred to in the section on Living Arrangements\textsuperscript{751}. The families of the female participants were much more active in their lives but this took very different forms. BIHLE4’s family

\textsuperscript{747} This is in contrast to only three NI lived experience participants whose references were very brief and did not warrant specific discussion. Only NILE2, NILE3 and NILE5 referenced family support, March and April 2016, transcripts on file with researcher.

\textsuperscript{748} Extract from interview with BIHLE4, 10 May 2016, transcript on file with researcher.

\textsuperscript{749} Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher.

\textsuperscript{750} Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher.

\textsuperscript{751} Section 4.3.3.
invested resources, time and effort to equipping her with skills to live a full life while BIHL3’s family confined her to the home. Where the male participants were accommodated within a family structure this was done with no reports of limitations on their day to day activities at any stage.

4.2.5 Education

Rouse, Florian and Connolly make brief reference to the nature of special needs education in Bosnia as being a system inherited from the former Yugoslavia with segregation being the norm and the ‘defectology’ approach being used\(^{752}\). All of the participants engaged in education to some extent. BIHLE1 and BIHLE2 participated in mainstream education and they reported experiencing the natural social connections that arose from that\(^{753}\). The urban/rural divide in education before the war also featured in Rouse, Florian and Connolly’s report which describes how stigma contributed to families preventing children from continuing their education\(^{754}\). BIHLE3’s experience resonated with this as her support worker indicated that she was denied the opportunity to access education\(^{755}\). The table below outlines the educational experience of the participants.

Table 12. Education in BiH.

<table>
<thead>
<tr>
<th>Education</th>
<th>Total Disability Segregation</th>
<th>Mainstream</th>
<th>Religious and disability segregation</th>
<th>Gender Segregation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
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</tr>
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<td>Male</td>
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<tr>
<td>Female</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
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</table>

While Phillips argues that the focus on vocational training rather than higher education was a USSR policy\(^{756}\), Bacevic suggests that vocational training was a failed policy of the SFRY

\(^{752}\) Rouse, Florian and Connolly, External evaluation of the project, ‘Special Classrooms for Children with Disabilities in Bosnia and Herzegovina’ 1997-2000, available from: \(<https://www.unicef.org/evaldatabase/files/BHG_2000_007.pdf>\)., accessed 3 October 2016. The authors describe defectology as a multi-faceted approach to education which is extremely positive and effective, despite the negative connotations with the term.

\(^{753}\) Extract from interview with BIHLE1, 7 May, and BIHLE2, 9 May 2016, transcript on file with researcher.

\(^{754}\) Ibid.

\(^{755}\) Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher.

which sought to move away from academic instruction\textsuperscript{757}. Given that BIHLE2 did not receive his disability diagnosis until adulthood, his completion of ‘practical courses during his high school’ indicates that mainstream education had a vocational focus, as well as the emphasis on vocational training in segregated educational settings. This is further evidenced by BIHLE4’s account of a workshop style education in her special education school:

BIHLE4: Knitting basically, to become a seamstress. But she wasn’t good at it. She didn’t graduate in that school. She never completed her education. They had some workshops there in the school, knitting tapestries or carpets. She enjoyed it. She gave her mother the first tapestry she made as a present. Some of the things they gave as presents. BIHLE4 also had knowledge of others who had been institutionalized as children and had difficulties adjusting to an education system outside of the institution\textsuperscript{758}.

Later in the interview, BIHLE4: Her friend (name) who attended workshops together with her was also in (X institution). She was an orphan, didn't have parents. She says that her friend (name), said it was hard when she first came back from the institution, she made some friends. She got along well with the person in charge of her.\textsuperscript{759}

BIHLE5 received special education due to his perceived behavioural difficulties which staff had not assessed as being connected to his disability.

BIHLE5: He went to special school. But that was a mistake because there was nobody to send him to regular school so they sent him to special school. So he finished special school. He says that it was ok. The school it was ok. He said that unfortunately they didn’t teach them foreign language for example English. But he is satisfied with his school because he knows reading and writing.\textsuperscript{760}

The differences in living arrangements and family support followed through to education and leisure activities during the participant’s childhoods. Experiences ranged from full immersion with non-disabled peers and the general community (BIHLE1, BIHLE2), limited contact with disabled peers at a segregated school and institution (BIHLE4, BIHLE5) to limited interaction with the community upon completing an equivalent level to primary education (BIHLE3). More literature has become available on special needs education in Bosnia since

\textsuperscript{757}Rouse, Florian and Connolly’s ‘Education, conflict and class reproduction in socialist Yugoslavia’, Social Inequalities and Discontent in Yugoslav Socialism’, Edited by Rory Archer and Igor Duda, at p.78.

\textsuperscript{758}Extract from interview with BIHLE4, 10 May 2016, transcript on file with researcher.

\textsuperscript{759}Ibid

\textsuperscript{760}Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher.
the war ended and aid programmes have been evaluated. UNESCO International Bureau of Education highlights the role of international organisations working in the area in the aftermath of the war to promote inclusive education but notes that the highly bureaucratic nature of governance hinders full implementation of successful programmes.

All participants were in their early twenties when war broke out and this section will examine their experiences of the conflict. Saric and Rodwin are sceptical of the idea that a multitude of religious and ethnic groups were cohabiting peacefully in SFRY before the conflict. However, there was no indication of ethnic tensions from the qualitative research. Participants referred to school mates and living in the community with people of different ethnicities peacefully. Only BIHLE3 indicated any reservations about interacting with people from different backgrounds during her youth and this was connected to religious observance and gender rather than based on discrimination or racism.

BIHLE3: No, she would only say hello to them and go further. And there were no further interactions between her and people from other ethnicities. She had no friends. She was mostly friends with Muslims. Basically she wasn't friends with Croats or Serbs - that is what she is saying.

The opinion of the male participants was of particular interest, considering their future involvement in the conflict. Again, no male participant had ill feeling towards persons from other ethnicities and the reasons for war were not understood by them.

BIHLE5: [H]e doesn’t understand why we need have a war because he doesn’t have a hate in his self.

This was a cause of significant mental anguish for BIHLE1 who described the events at the start of the war very animatedly.

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761 Ibid
764 Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher
765 Ibid
766 Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher
BIHLE1: I didn’t hate anybody, never. I had my friends in school – Muslims and Serbians. And that’s how I was raised, they’d been my friends… But when the war started I was going through that, it was like a whole movie for me. [Acts out motions]. He was so, he didn’t know what to think, what to do. I need to go in war, I don’t know what will happen. [Mimics noise of explosion] There was no other solution.

BIHP5 reported that there was significant confusion around the reasons for war among the general population and suggested it would be harder to understand for a person with an intellectual disability.

I know from a few examples that also they couldn’t grasp the concept of the conflict and the reasons. No one could. I can’t. But those concepts were also very difficult for them. It made it even more stressful for them than for others, they were completely excluded from any discussion, any decision making process. I would say they were more disadvantaged than the others.

The 1991 census provided the most recent population data available before the outbreak of war. The population of BiH at that time consisted of a Muslim majority, followed by Serbs and Croats as the dominating ethnicities. Following the dissolution of the SFRY, a tripartite coalition government was formed with representatives from Bosnian Muslims, Bosnian Serb and Croats. This was an uneasy political situation with Bosnian Serbs establishing autonomous regions of solely Bosnia Serb inhabitants throughout the country, creating ethnic divisions. Parallel to these divisions, events external to Bosnia – declarations of independence from the SFRY by Croatia and Macedonia – led to a referendum on independence from SFRY. This was easily passed despite the very low participation of Bosnian Serbs who were not in favour of independence. Buyse and Hamilton

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767 Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher
768 Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher
769 Ibid
note that the judicial structures established through the 1963 Constitution were adapted to Constitutional Courts in the individual states after the breakdown of the SFRY.

4.3 Section 2: Period of conflict (1992-1995)

In April 1992 the EU and the U.S. recognized Bosnia as an independent state. Efforts to establish local governance structures known as cantons were unsuccessful due to objections from all three ethnically aligned political groups. In the same month, Bosnian Serbs, supported by the Yugoslav Army, initiated armed conflict against areas with significant Bosniak populations. These targeted attacks were subsequently recognized as strategies of ethnic cleansing.

Due in part to the extremity of the violence perpetrated by all armed forces, the Bosnian war received intense media coverage at the time and has been subject to significant academic, policy and legal scrutiny since then. The events have contributed to discourse on armed conflict, peace processes, gender based violence, economic recovery and the role of the media. A wide variety of sources from the desk-based research documented the disruption to fundamental services, food and essential supply shortages. There is also considerable focus on the conflict as a cause of physical disability but it was not possible to locate accounts of experiences of persons with intellectual disability. None of the lived experience participants resided in an institution during the war so I was reliant on the perspectives of the professionals to address this gap in the literature. These are incorporated into the discussion below.

4.3.1 Conflict Experience of persons with intellectual disabilities

*Table 13. Conflict Experience of persons with intellectual disabilities experience BiH.*

<table>
<thead>
<tr>
<th>Conflict Interaction</th>
<th>Military service</th>
<th>Civilian</th>
<th>Knowledge of someone serving</th>
<th>Knowledge of deceased/injured</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>3</td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>2</td>
<td>1</td>
<td>2</td>
</tr>
</tbody>
</table>

Each of the male participants served with their respective ethnic forces with only BIHLE5 indicating any choice on this matter – he chose to serve a portion of his military service in Croatia. BIHP5 indicated that serving in the military was considered a duty and there was a sense of shame attached to men who did not serve.

**BIHP5:** *I know of another example of a family friend with an intellectual disability, he was scared for military service which was then seen for some people by 'lucky you’, you have this special benefit because you are not [eligible for combat]. So there was this not really favourable opinions of them because they were seen that they were not contributing to the struggle. The confusion and disruption caused by the conflict to the general population was recounted by several participants. Daily life, homes and agricultural lands were totally abandoned.*

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783 Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
BIHLE1: They were confused and didn’t know what to think, what to do in that time. Very scared they needed to run from their houses and left everything. The animals like cows, sheep and pigs what they had in their villages were just walking around.  

While the civilian population struggled to find adequate food and shelter, the reports from the former soldiers among the lived experience participants was that there were adequate provisions in the military. Bougarel discusses how providing basic food and healthcare was necessary to motivate soldiers not to desert the armed forces. Military training was provided by all armed forces but the training period was often brief due to the nature of the conflict. Shrader notes the aspirations of the Bosnian Croat and Bosniak forces to provide specialized training to individuals alongside ambitious training schedules. However, this was not reflected in the reality recounted by the participants in the lived experience group. Although the events of the war were chaotic and extremely violent, it was not an amateur operation. While some soldiers did not participate through their own volition, contracts were signed and career progression was offered with the armed forces.

BIHLE1: We needed in that time to sign a contract for three years. After that they make his contract longer than three years, in army they have different counting time. One year counts as two years in the work for the army. During that time in the army he go with that, was in Turkey for three months on some kind of training with the army airplane. We spent three months on that training. For that time they paid me. I have good salary.

BIHLE1 described the varied nature of his work, the considerable travelling and the impact he saw on the terrain and the lands that he was familiar with before the war. He was also concerned about the widespread impact of the war, referring to other towns that had had worse experiences. While some alliances were formed between Bosniaks and Bosnian Croats encountering ethnic cleansing carried out by Bosnian Serb forces, these were short-lived. This is reflected in BIHLE1’s experience. He witnessed the targeting of the Bosniak population by the Bosnian Serb forces but also admitted that any allegiances were

784 Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher.
787 Extract from interview with BIHLE1, May 2016, transcript on file with researcher.
complicated and blurred as Bosnian Croats and Bosniaks both engaged in property destruction and looting.\footnote{Extract from interview with BIHLE1, May 2016, transcript on file with researcher}

BIHLE1: The situation in other towns was even worse than here. They go there, on first line where there was just a stone, there wasn’t any trees or anything and it was difficult to hide. Snakes and scorpions, they didn’t have injections for the snakes so it was scary for him.... Really crazy, people panic and people couldn’t, even fighting between them because they’re so afraid, it was so crazy in that time. All the children and old people and women, they all get together in this local town. Refugees from other villages and that was so difficult. That time he was able to see how the Serbian people were grenading the Muslim people all the time, in Sarajevo all the time. They were just sitting and waiting. Didn’t know what would happen next. And then the war start and the Croatian people started turning [looting] the houses of the Muslims and taking stuff. And also the Muslim people were burning the Croatian houses.\footnote{Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher}

BIHLE5 was not recruited to the army as early as the other participants, having sought asylum unsuccessfully in another jurisdiction. BIHLE5 was more fortunate than the other male participants as he had the opportunity to be moved to what was deemed a less dangerous section of the armed forces in Croatia after his initial training period. However, he stated that not having the period of military service in Croatia recognized by BiH authorities resulted in his being institutionalised after the conflict. He was less positive about medical attention provided to him in Bosnia than the other male participants but was satisfied with his treatment in Croatia.

Throughout the interviews there were references to family members, neighbours and friends fighting alongside the soldiers, including female combatants also. Hunt’s qualitative research with Bosniak women after the war suggests that women’s participation was not even known to some people who lived through the war.\footnote{Hunt, S., ‘Muslim Women in the Bosnian Crucible’, Sex Roles (2004) Vol. 51, Nos. 5/6. Some participants in this article gave an account of their perceptions on the differences of men and women’s attitudes to killing while serving in the armed forces during the conflict while others contribute their opinion that while women didn’t contribute to creating the tensions or serve during the war, they suffered most. BIHLE1 expressed surprise at encountering female Muslim combatants.} Bosniak women’s participation in conflict was referenced during an interview also.\footnote{Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher}
BIHLE1: Even women on Muslim side were trained to go to war because they must go to war. In [local town] only men go to war not women.793

The toll of the violence on BIHLE1’s family and friends was clearly weighing on his mind as he told his story and the desk based research had not fully relayed the extent of the personal traumas endured through the conflict.

BIHLE1: In 1993 was killed his uncle’s son. And his godfather. His friend also died from grenade. Died one girl from grenade and he was there and he was watching all of that with his eyes...Some of my friends died and they’re not alive now and I feel sorry for that.794

For the female participants the war was experienced differently to the men as they did not serve in the armed forces. Their interaction with violence was as civilians. Where there had been significant differences in their lives up to this point due to differences in socio-economic status and geographic location, both female participants experienced shortages of basic supplies and recalled the danger from the conflict. While BIHLE1 had described witnessing towns and villages being abandoned as a soldier, BIHLE3 was never forced to flee her home as a civilian. Precautions had to be made to avoid being injured. BIHLE3 recounted the constant fear she experienced during the conflict. As she was mostly confined to the family home throughout her young adulthood (primarily for reasons related to religious observance), some sense of normalcy remained with daily activities continuing. However, it would seem that for people with more extensive social networks, the experience of not being able to travel through the community unimpeded during the conflict - to attend school, work and leisure activities – would be a difficult transition.

BIHLE3: They were living in poor conditions, had no money, everybody was screaming ‘go run in the shelters’. They were hiding in basements. A lot of people here were hiding in the basements. She is joking how they were bringing carpets and mats. She is just joking how when they were going to these basements they were also bringing furniture with them. Sofas, carpets. Just moving the house downstairs.

Supporter: Yes, but she is retelling it in a funny way so we are laughing, I am sorry.

Did you know that the war would start?

793 Ibid
794 Extract from interview with BIHLE1, 7 May 2016, transcript on file with researcher.
Yes, she was aware. It messes with your head, that's how she explains it. She feels better now that she is here in (town).

Did you know anyone who fought in the army?

*Her brother was in the military.*

Later she said: *[S]he basically did all the same everyday chores like cleaning, doing the dishes, cooking, making pastries.*

BIHLE4 had a similar experience to the other participants in urban areas having known people who died and experiencing more disruptions to daily life. She explained how the confusion and fear around the attacking army approaching was made worse by the power outages which were used as a tactic of the Bosnian Serb army. This disruption to vital services is echoed by Demick, a journalist in Sarajevo at the time of the war, who provides an account of the experience of the media in an urban area.

**BIHLE4:** Yes, she was here during the war. Her friend died in war, she was close as well. She was 16 years old when she died. Her uncle also died in the war. A grenade hit him and he died. That's about it regarding her war. When they were carrying water, the grenades were – the grenades almost hit her mother when they were collecting water. When they were returning home.

And did you always live in your house or did you have to move?

**BIHLE4:** Yes, she was here with her parents all the time.

And was your house ever damaged?

**BIHLE4:** No, her house wasn't damaged. She first lived in a skyscraper in (town) and then she moved to another apartment. But it was all here in (city).

Could you talk to people, did you feel comfortable talking about the different groups with your family and friends?

**BIHLE4:** She was mostly talking to her mother about the Bosniak forces fighting the Serb forces. They were also hiding in basements. That was a common case in (city) – if their

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795 Extract from interview with BIHLE3, 9 May 2016, transcript on file with researcher.


neighbourhoods were being bombed they would usually take refuge or shelter in the basements. She is talking about the lack of electricity, she didn't have electricity. There were many occasions they were very frightened somebody was knocking on their doors and they didn't have the electricity so they thought that the Serb forces came. Towards the end of the war, in 1993 the electricity came back. Without electricity you don't know [who was approaching the home]797.

The conflict impacted on the lived experience participants in a significant way. Participation in the armed forces was expected of the male participants who witnessed death of relatives, friends and colleagues as well as the displacement of peoples and destruction of properties. Female participants also experienced loss and fear while trying to stay safe in their homes and access to basic necessities such as food and water were severely limited. No participant availed of a disability service during the conflict so the research relied on the contributions from the professional participants, which will be discussed now.

4.3.2 Disability services during the conflict

Coyne798 describes how the experiences of children and adults in state institutions during the war remains hidden. She is critical that historical organisations and museums have neglected these experiences given the significant impact conflict had on the continuation of institutional care for persons with disabilities. The professional participants recounted that only very basic services were available, primarily in institutions, and most professional participants agreed that the war negatively impacted service provision. However no participant indicated that they had personal experience with disability services during the war so their impressions are based on anecdotal evidence. However, in the absence of any other information their contribution does go some way towards creating a picture of the impact of the war on institutionalised persons with intellectual disabilities. When discussing sectarian discrimination in disability services during the war, three professionals acknowledged the role of religious orders providing humanitarian relief to civilians during the war. Persons with disabilities would have benefitted from these activities but in their view the delivery of aid was not conducted in a discriminatory manner.

797 Extract from interview with BIHLE4, 10 May 2016, transcript on file with researcher.
BIHP4 relayed the experiences of people he had worked with, while he himself was a refugee in another jurisdiction. He described the shift in focus from disability service provision to distribution of humanitarian aid.

BIHP4: *These organisations, DPOs*[^799], *were devastated to that extent that even archives were used as a heating material. Everything was actually based on raising humanitarian aid and food. When it comes to organisations, they were dedicated to raising money for food, clothes and basic necessities. Occupational therapies and disabilities services were left on the margins... So these organisations they did exist but they were focused on providing humanitarian aid, they were focused on that and not on providing disability services. He is talking about local DPOs not taking into consideration international organisations but he’s only rephrasing, retelling other people’s experiences, not his own.*[^800]

BIHP3 had a different perspective on the resources available to residential institutions for persons with disabilities during the war. She suggested that the large buildings were attractive bases for international aid agencies to deliver supplies and the residual supplies could then be distributed to the community. She went so far as to suggest that people in the institutions fared better than the general community, as there was some safety from bullets, snipers and bombs.

BIHP3: *It is mostly survival instincts during the war. They [persons in institutions] weren’t left on their own, left aside. They did have disability people’s organisations providing them with support, be it the deaf, those with intellectual disabilities, the blind people. They would have been financially supported by international organisations and projects during the war. Owing to financial support from international organisations, people with disabilities who were placed in closed type institutions were even given better qualitative services than the rest of the citizens, better clothes and better food. There was given that much food that they were even able to give it to other people who [were] lacking it.*

Were institutions ever targeted by bombs and stuff?

[^799]: The term ‘DPO’ was used incorrectly here as it did not refer what is understood to be a Disabled Persons Organisation. Disability Rights Fund defines DPOs as: Disabled persons’ organisations or DPOs are representative organisations or groups of persons with disabilities (P WDs), where P WDs constitute a majority of the overall staff, board, and volunteers in all levels of the organisation. Disability Rights Fund, ‘What is a DPO?’ available from: <http://disabilityrightsfund.org/faq/what-is-a-dpo/> accessed 7 November 2017.

[^800]: Extract from interview with BIHP4, 6 May 2016, transcript on file with researcher.
BIHP3: No. The Centre for Social Work was bombed. The cantonal ministry of Sarajevo was devastated. It was a completely new building before the war but it was bombarded and completely devastated after the war. There was a lot of shelter, [in] an institution. It was a shelter for many people but it wasn’t bombarded. Slightly but not completely devastated. 801

BIHP5 also highlighted the role of staff who remained in institutions during the conflict but offered a contrary perspective concerning the provision of supplies and support. Both she and BIHP3 agreed that the commitment of the staff was vital to the survival of residents.

BIHP5: Exactly. It was like just because the conditions were awful. So obviously they were much more affected in those regards just because they received zero support. So they did have staff members who were determined to stay and stick around and stay with them. And thanks to the special efforts of those staff members those who had survived had survived otherwise they would have just been left to their own devices. If the staff hadn’t stuck around they would have been left to their own devices and probably a lot of them would have died from hunger or whatever. So that was a very bad event. 802

As is evident from the accounts from the professional group, international aid was a lifeline for citizens. The United Nations peacekeeping efforts met severe opposition despite coordination with NATO forces and humanitarian aid remained undelivered to those most in need 803. These actions were heavily criticised by the international community and human rights organisations 804. Staffing of disability institutions is one area where the ethnic tensions were obvious during the war. The majority of Serb staff left certain regions and Croats and Muslims remained 805. While the war created refugees from all ethnic backgrounds, Sell suggests that up to 90% of Serbs who had resided in Sarajevo had fled during the war 806.

BIHP3 had no knowledge of persons with intellectual disabilities being involved in the conflict. Another member of staff of a disability rights organisation, acting as an English language support for BIHP3, contributed some of his own knowledge and BIHP3 was

801 Extract from interview with BIHP3, 6 May 2016, transcript on file with researcher.
802 Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
805 BIHP5, August 2016, transcript on file with researcher.
satisfied for him to make contributions in English. She was the only participant to suggest that disability services continued throughout the war.

Supporter: [I] personally know some beneficiaries of [institution X] who participated in war, by volunteers not systematically.

Do you think they were preyed on because they had a disability and maybe they were an easy target?

Support: They were not treated as any kind of people with disabilities, just as a soldier. You mean picked on? They weren’t forced, it was strictly voluntary.

Going back to what you said earlier – you said there had been community houses, did those people have to go into institutions, were they forced back in when they had been living semi-independently were they forced back into an institution?

BIHP3: Nobody was transferred from those communities during the war. She is only talking about the pre-war situation.

So then how were their services impacted during the war?

BIHP3: So if they lived with their families their status and situation remained unchanged. However throughout the war all these DPOs were very active in providing support, providing disability services from psycho-social support and others sorts of supports. They were never left aside or on the road. 807

This assertion of continuous support for persons with disabilities during the war was challenged by other participants. The extent of deprivation during the winters of the sieges in Sarajevo recounted in the literature suggests that continuous support for persons with disabilities would have been very difficult, if not impossible, during the height of the conflict there808.

BIHP5: It was the period when [the family] couldn’t just leave and go visit. So there was no food, no heating, conditions were terrible. It was awful. It was terribly cold. A few people had died during those few harsh war winters... There was also intersectional discrimination. A

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807 Extract from interview with BIHP3, 6 May 2016, transcript on file with researcher.
few examples that I’m aware of, where they were members of minority groups in wherever…..Plenty of bullying, not to mention anything more serious.809

The accounts above of life during the conflict addresses a significant gap in current literature in relation to the experiences of persons with intellectual disabilities in BiH during the conflict, with limited insight into the experiences of those living in institutions at the time810. It is clear that persons with intellectual disabilities who were not institutionalised had similar experiences to the non-disabled population. Involvement in armed conflict by the male participants was demanded by social expectation with the former soldiers reporting not having any motivations to engage in violence against persons from different ethnic backgrounds. The women participants were exposed to violence as civilians and struggled with shortages of fundamental supplies. Reports of conditions for persons with intellectual disabilities within institutions were conflicting which suggests regional differences in how institutions were affected.

In 1995 concerted efforts by NATO and Croatian armed forces pressured Bosnian Serb representatives to join peace talks toward the end of the year and the General Framework Agreement for Peace in Bosnia and Herzegovina811, also known as the Dayton Accords, were signed812. This was facilitated by U.S. intervention with President Bill Clinton and was predicated on a renewed policy to implement airstrikes against Serb forces if the ceasefire was reneged upon813. The peace agreement was named after the location of the talks in Ohio, USA where talks occurred between the three presidents: Izetbegović for the Republic of BiH, Tudjman for the Republic of Croatia, and Milošević for the Federal Republic of Yugoslavia814.

Article I of the Accords brought a cessation to the conflict by requiring the parties involved to resolve any future issues in accordance with the United Nations Charter. Article V established the Constitution of BiH while Article VI establishes mechanisms for arbitration

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809 Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
814 Ibid
and future human rights and equality monitoring through thematic Commissions\textsuperscript{815}. There is much written\textsuperscript{816} - positive and negative - about the chain of events leading to Dayton, the various actors such as the EU, the impact of arms trade regulations,\textsuperscript{817} but while informative, these accounts are not the focus of this research. Only one participant from the professional group made their perceptions of the peace process known. She was very critical about the way in which the peace agreement came about.

BIHP5: Dayton Peace- the constitution of Bosnia Herzegovina, which was actually, it was drafted that way as part of the peace making process. The constitution has never been translated and published in the official Gazette. So this tells you how transparent the process was. Twenty years after the war it has never officially been translated from English, so our constitution is only in English. Its accessibility to the population in general [is low], not to mention there is no easy to read or any other attempt to make it accessible to persons with any kind of disabilities, not to mention persons with intellectual disabilities. The process was not inclusive for the majority of population. It was just a few warlords who sat down and put their signature on a piece of paper that was prepared by the Americans. So no one had much to say about it.\textsuperscript{818}

The next section will discuss the provisions contained within Dayton and the system it established post conflict.

4.4 Section 3: Post conflict (1996-2010)

Despite BIHP5’s criticisms of the Dayton Peace Accords, the far-reaching implications of peace agreement cannot be understated. The Accords are directly responsible for the system of governance within BiH today. The peace agreement sought to appease the mistrust which the conflict had created between the ethnicities in BiH. The overarching government, led by a tri-partite presidency\textsuperscript{819}, of the state is responsible for issues such as foreign policy, trade, immigration and refugee systems. The state of BiH is divided into two main entities: the

\textsuperscript{815} Ibid
\textsuperscript{818} Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
Federation of Bosnia and Herzegovina and the Republica Srpska. There is a third smaller entity, the Brčko District. It was intended to be a multi-ethnic state, which was created in the aftermath of Dayton due to the complexities in the region. The entities are responsible for assisting the overarching government in achieving and complying with standards on international and domestic affairs. They are also tasked with maintaining law enforcement agencies that adhere to international standards. The Federation of Bosnia and Herzegovina is further divided into 10 cantons, each with their own governance structures. Significant powers were devolved to the two entities, and further again within the FBiH.

Annex 6 of the Dayton Peace Accords outlined human rights obligations going forward, aligning itself closely with, but not fully incorporating, the European Convention on Human Rights. The Accords also established a Human Rights Commission. The Human Rights Commission is divided into the Office of the Ombudsman and the Human Rights Chamber. This combined body has the power to investigate alleged human rights violations on multiple grounds such as gender, ethnicity and religion (although there is no reference to disability as a ground) perpetrated by any state organ. The Commission can receive complaints from any individual or organisation, statutory or non-governmental, and can issue reports of findings to relevant government bodies. The Human Rights Chamber was composed of 14 members, a mixture of representatives from the entities and independent non-Bosnian jurists, and served as a human rights specific court but ceased operation in 2003.

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824 European Convention on Human Rights encompassing the right to life, freedom from torture inhuman and degrading treatment, right to liberty, freedom from slavery, fair procedure in criminal and civil legal matters, right to privacy and family life, freedom of thought, conscious and expression, right to peaceful assembly, right to marry, property, education and free movement are referred to explicitly in the text of Annex 6.
826 This mandate of this office ceased in 2003 and was succeeded by the Human Rights Commission within the Constitutional Court of Bosnia Herzegovina. Human Rights Commission within the Constitutional Court of BIH, <http://www.hrc.ba/> accessed 15 January 2018.
The qualitative research conducted was limited to participants in three cantons of FBiH. All of the professional participants reported significant frustration with how the complexity of national, regional and local government administration affects disability service provision. The Directorate for European Integration is effective in illustrating the multiple layers of governance. Social policy, health, education and labour are among the mandates over which each individual canton has control so it was clear from very early on that a comprehensive analysis of each disability related provision, policy and legislation applicable in each of the cantons would not be feasible in this research.

BIHP2 aptly summarized the inadequacy of relying on a framework intended to cease the armed conflict for the long term administration of a state.

BIHP2: These issues of persons with disabilities are tightly connected to the economic, political, the general situation in Bosnia Herzegovina. Following the peaceful processes all these national political elites are trying to retain their current positions so the other problems are not being tackled. They are left in the margins, hanging in the balance.

The most significant impact of the Dayton Peace Accords was the cessation of armed conflict. BIHLE1’s experience indicates that the peace process did not bring an immediate end to his military service. At the time he was unclear about the peace negotiations or what Dayton would mean in practical terms other than a cessation of armed conflict. Considerable work was still to be undertaken with United Nations forces to ensure safe passage for civilians and soldiers through former enemy territories.

BIHLE1: [I was told about the Dayton Accords] from the high people in the military. They connected them and said there is Dayton agreement, you should stop fighting. So then the UN army they make barricades and work together with Croatian, Serbian and Muslim army so people could walk out of there. And then it starts slowly peace. People stopped being on

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828 This mandate of this office ceased in 2003 and was succeeded by the Human Rights Commission within the Constitutional Court of Bosnia Herzegovina. Human Rights Commission within the Constitutional Court of BIH, <http://www.hrc.ba/> accessed 15 January 2018.

829 Schematic overview of levels of governance in Bosnia and Herzegovina, Directorate for European Integration – Division for Harmonization of the Legal System of Bosnia and Herzegovina with the Acquis has prepared an overview of the levels of governance in BiH for informative purposes. <http://www.dei.gov.ba/dei/dokumenti/uskladjivanje/default.aspx?id=13859&langTag=bs-BA> accessed 15 November 2016

830 Ibid.

831 Extract from interview with BIHP2, 6 May 2016, transcripts on file with researcher.
the first line and went back to their homes. Dayton ended the war. He was so happy and he thanks God.832

From the accounts of the participants, there did not seem to be a desire for an armed conflict among civilians and it was the actions of politicians which created the ethnic tensions. BIHLE1 believed that war came about because of the failings of the Yugoslav politicians who could not settle ethnic disputes without war. He felt he had no choice about participating in the conflict but that he, along with everyone else, had to accept it.833 It was problematic for members of the different armies and the general population to trust each other again and BIHLE5 was conflicted in his opinion of the UN’s role834. BIHLE2 was also serving in the military when he heard about the Dayton Peace Accords and was pleased at the announcement835. Both BIHLE2 and BIHLE5 terminated their service with the armed forces immediately after the Dayton Peace Accords were announced. Later in the conversation we discussed the impact of the conflict on ethnic tensions. BIHLE2 asserted that there was some mistrust among the different ethnic groups that exists currently. His support person provided examples of activities which could incite ethnic tensions – public events and parades were given as examples.

BIHLE2: Yes, it was hard to assimilate to the new situation, to accept different ethnic groups.

And now do you think people are prejudiced against other groups?

BIHLE2: According to him yeah, they are still prejudiced.836

BIHLE3 had had limited exposure to information about the peace process so the conversation on the topic was limited. She did however indicate an overall sheltered-ness that arose because of a combination of religious observance and her disability. BIHLE3’s experience indicates the difficulty and shortcomings in participation in society was also due to pressures exerted on her from her immediate family.

BIHLE3: She is expressing her patriotic beliefs and how she loves this country. After she got married she never voted again.

How come?

832 Extract from interview with BIHLE1, 3 November 2016, transcripts on file with researcher.
833 Extract from interview with BIHLE1, 7 May 2016, transcripts on file with researcher.
834 Extract from interview with BIHLE5, 3 November 2016, transcripts on file with researcher.
835 Extract from interview with BIHLE2, 9 May 2016, transcripts on file with researcher.
836 Extract from interview with BIHLE2, 9 May 2016, transcripts on file with researcher.
BIHLE3: *Because her husband wasn’t very supportive of the idea of her voting for anybody. Because of her husband, he didn’t allow her to vote.*

BIHLE4 admitted to having limited knowledge about the peace process and the conversation quickly moved on to another topic. She reported only positive feeling toward people of other ethnicities and gave an example of a Catholic friend. BIHLE5’s discussion of Dayton was brief. He reported that after the war there were no ethnic tensions within the institutions he was placed in and that there have been positive changes. This could be due to the changes in his own personal circumstances of being supported out of institutionalisation however.

BIHLE5: *Yes, they would have had friendships between all of them, doesn’t matter if they are Croatian, Bosnian or Serbian. That was the all of the [institution] building.*

BIHLE5’s experience of accessing health services as a soldier seems more positive than civilians’ experience. This is supported by the accounts from Bosnian professionals regarding the prioritisation of armed forces in the aftermath of conflict. While only one participant in the professional group gave their perception of the peace process referenced earlier, BIHP3 referred to the geographical difference of the impact of the Dayton Accords on the lives and rights of persons with disabilities.

BIHP3: *It depends on the particular region. For example in these bigger cities such as (named city) or (named city) the situation is slightly better. When it comes to rural places, smaller villages, post war situation is more negative. It brought more consequences in eastern Bosnia for example. Refugees are not very welcome to be returned to their home place. They are being molested or forced not to return actually. He is emphasizing the extent of discrimination towards persons with disabilities in particular. For example if they are refugees then they’re discriminated, they’re poor and also they have disability. In these rural, very distant regions, this discrimination is more pronounced on a triple basis. Not in (named city) we are talking about. There’s social protection in (named city), the discrimination is not that pronounced.*

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837 Extract from interview with BIHLE3, 9 May 2016, transcripts on file with researcher.
838 Extract from interview with BIHLE4, 10 May 2016, transcripts on file with researcher.
839 Extract from interview with BIHLE5, 3 November 2016, transcripts on file with researcher.
840 Ibid
841 BIHP1 and BIHP5 referenced the preferential discriminatory treatment of persons with disabilities based on military service. May 2016, transcripts on file with researcher.
842 Extract from interview with BIHP3, 6 May 2016, transcripts on file with researcher.
Based on the qualitative research and literature review, the end of the conflict did not result in a cessation of the factors that contributed to the conflict. Discrimination and the multiplicity of characteristics – gender, disability and, depending on the region, ethnicity contributed significantly to the experiences of the participants. These practices are a prime example of the effect on the ground of a lack of consultation with citizens affected by the conflict to bring about a resolution.

Overall, the Dayton Peace Accords were warmly welcomed by all participants as it meant an immediate stop to violence but not necessarily a cessation of all military activities. There was a mixed response to the issue of continued ethnic tensions. Generally personal experience was that it was not an issue, but when the questions related to the broader or national situation then there was more scepticism. O’Tuathaill’s discussion on the tenth anniversary of the Dayton Accords analyses in significant detail the mistakes made – rewarding ethnic cleansing by creating a separate Republica Srpska of majority Serb ethnicity, the non-compatibility of the newly drafted Constitution of BiH with the European Convention on Human Rights, the excessive bureaucracy and the non-democratic legitimization of the newly formed entities and cantonal divisions. From the interviews with the participants it is clear that these issues featured heavily in their day-to-day lives but the confusion and uncertainty around the political situation was compounded by their disabilities.

Sterland estimates that 100,000 Bosniaks were killed through ethnic cleansing during the conflict. However, Tabeau and Bijack indicate the difficulty in determining the exact number of people who died in the conflict due to unreliable sources. They suggest a much lower number of 102,622 deaths to include all ethnicities over the period of the conflict. The International Criminal Tribunal for the former Yugoslavia was established in 1993 and its work has been crucial in determining the extent of human rights violations and criminal liability for actors during the conflict in the region, including the events within BiH.

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843 It facilitated discrimination against persons with disabilities through segregated education and differential remuneration of social welfare based on type and origin of disability.
845 Participants with lived experience who had served in the armed forces relayed accounts where some ceased their service immediately and others continued.
International Criminal Court for the former Yugoslavia completed its work in 2017 having prosecuted the crimes of genocide, crimes against humanity, violations of the conduct of war and breaches of the Geneva Convention. The Mechanism for International Criminal Tribunals will now serve as a redress mechanism for those appealing their prosecutions under the ICTY.\textsuperscript{848}

4.4.1 Post conflict disability related legislation

There is no single piece of national legislation in BiH providing for disability services, the operation of social care institutions or Centres for Social Work.\textsuperscript{849} In order to ascertain how disability services are regulated in BiH, I have collated a sample of relevant legislation from within the FBiH and the Republica Srpska. This is outlined chronologically below. There are multiple sources referring to legislation within the entities which relate to disability but access to the text of the legislation is not available in English.\textsuperscript{850} Nationally, BiH does not provide funds for social services as these are financed and regulated at the local canton (FBiH) or municipality (Republica Srpska) levels. Activities funded at a national level are limited to services for asylum seekers and victims of trafficking within the state.\textsuperscript{851} The Constitution of Bosnia and Herzegovina\textsuperscript{852} also does not contain any specific reference to disability but it does guarantee that human rights are to be applied in a non-discriminatory manner.

In the Republica Srpska social protection structures are governed by the Law on Social Welfare 1996. In the absence of national guidance on social protection specifically, staff and civil servants in FBiH are obliged to adhere to the Law on Administrative Procedure from 2002 when making any decision affecting the rights, responsibilities and legal interests of Bosnian citizens.\textsuperscript{853} An almost identical provision is applicable in the Republica Srpska.\textsuperscript{854} This legislation contributes to the equality of treatment in the administrative process for

\textsuperscript{850} This was confirmed through correspondence with the Ombudsman, 21 August 2017, on file with researcher.
\textsuperscript{851} Ibid
\textsuperscript{853} Official Gazette’ of Bosnia and Herzegovina, No. 29/02, 12/04.
applicants to and beneficiaries of the social protection system, including persons with intellectual disabilities.

The first disability-specific legislation in the post-conflict era in Federation Bosnia Herzegovina (FBiH) is the 1998 Law on Modifications and Amendments to the Law on Pension and Disability Insurance of the Federation of Bosnia and Herzegovina. This was amended multiple times in 2001, 2002, 2005, 2006 and 2009. This was the primary provision governing main disability legislation for that period. This legislation related to social welfare benefits for persons with disabilities who could not participate in the workforce during those years.

The focus on disability acquired from the conflict was continued in FBiH through the 1999 Law on Core Issues of Social Care, Care for the War-Disabled Civilians and Care for the Families with Children. Articles 13 and Article 16 indicates that persons with intellectual disabilities are covered under this legislation. This legislation states that cantons will organize the activities of social protection institutions which will have legal status and these can be provided by the state or by humanitarian and religious organisations. The social protection regulated under this law includes financial support, training on work and life.

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856 Disability insurance legislation was subject to many amendments and regulation required detailed legislation. Examples of these are the Law on Receivables in the Privatization Process Based on Difference in Income of the Beneficiaries Exercising the Pension and Disability Insurance Rights (1998 and 2002), Law on Organisation of the Pension-Disability Insurance Fund in the Federation of Bosnia and Herzegovina (1999), Law Date File on Insurees and Beneficiaries of the Pension and Disability Insurance Rights and Law on Master Record on insured persons, persons obliged to pay contributions and beneficiaries of the pension and disability rights (2011).

857 Law on Core Issues of Social Care, Care for the War-Disabled Civilians and Care for the Families with Children, Article 13.5 includes as a beneficiary of the legislation a ‘person disturbed in mental or physical development and person with disability’.

858 Ibid, Article 16 further defines ‘Person disturbed in mental or physical development and person with disability, pursuant to this Law, is child or adult who is:

1. blind or with damaged eyesight
2. deaf or with damaged hearing
3. with speech and voice difficulties
4. with bodily damage and permanent difficulties in physical development
5. with difficulties in mental development (light, moderate, severe and very severe degree)
6. with combined difficulties (children and adults with multiple difficulties in development.

859 Ibid at Article 5
skills, residence within an institution or with another family, in-home supports or other social work services as required.\footnote{Ibid at Article 23.}

The Law of 1999 on Principles of Social Protection, Protection of Victims of War, and Protection of Families with Children in FBiH governs the eligibility of ‘vulnerable persons’ for social protection. This includes placement in an institution. Article 14 of this legislation outlines the applicability of the legislation to persons with intellectual disabilities and provides an entitlement for a range of interventions from financial support, foster care, life skills and occupational training, home assistance and institutionalisation.\footnote{Bosnia and Herzegovina: Law of 1999 on Principles of Social Protection, Protection of Victims of War, and Protection of Families with Children [Bosnia and Herzegovina], 6 September 1999, available from:<http://www.refworld.org/docid/4d30226f2.html> accessed 27 November 2017} It is at the discretion of each canton to determine what supports are provided.\footnote{Ibid at Article 2 and Article 8.} It outlines the requirement for a medical opinion to validate inability to work due to intellectual disability in accordance with cantonal regulations. An allowance is available for a person with an intellectual disability who requires the support of another person to go about their daily lives.\footnote{Ibid at Article 19.} The rate of this payment is based on the income of the household.\footnote{Ibid at Article 25.} As well as institutionalisation, placement with another family is an option for children, adults with intellectual disabilities and single mothers and their children. This law was amended multiple times and the most recent version was amended in 2009.\footnote{Ibid at Article 31.} The amendments served to alter the technical administration to harmonise the benefits within FBiH.\footnote{Organisation for Security and Cooperation in Europe, ‘The Right to Social Protection in Bosnia Herzegovina. Concerns on Adequacy and Equality.’<https://www.osce.org/bih/107168?download=true> accessed 15 November 2017.} Article 41 of this legislation provides for the placement of persons with disabilities in an institution in compliance with a court order or after medical assessment. There is no choice offered as to the institution. The costs associated with this placement revert to the parent, custodian\footnote{BIHP4 confirmed that a custodian could be an employee of the Centre for Social Work, representing the State. Extract from interview with BIHP4, 6 May 2016, transcript on file with researcher.} or relative of the person with a disability and are determined by the founder of the institution. It is clear from these two 1999 laws that there was duplication in the provisions for social services which include persons with intellectual disabilities, and that institutionalisation is conceived of as a valid state response to the social support needs of persons with intellectual disabilities.
The Law on Protection of Persons with Mental Disorders in 2001 and 2002 in FBiH has the effect of removing the legal capacity of persons within social protection institutions\(^{868}\) if admission to the institution is based on a psychiatrist’s instruction followed by a court order. The corresponding law in Rep. Srpska came into force in 2004. These laws set out the operation of social protection institutions for persons with disabilities and regulates voluntary and involuntary admission to institutions\(^{869}\).

The legislation discussed above demonstrates that there were numerous provisions across FBiH and Republica Srpska in the decade after the conflict which governed services typically availed of by persons with intellectual disabilities. These were influenced from the pre-war era of rehabilitation for participation in the labour market and retained a paternalistic attitude of services.

4.4.2 Post conflict disability services

Having attracted international attention on the atrocities of violence and rights abuses, the recovering state of BiH received funding from the World Bank\(^{870}\). This collaboration resulted in the identification of disability as a priority issue and the need to reform the national rehabilitation and health services to include quality community based care\(^{871}\). While this strategy intended primarily to address the physical disabilities acquired by citizens during the war, the themes of independent living had the potential to be incorporated within intellectual disability services\(^{872}\). Unfortunately, this was not the case as reported by the participants in this research. BIHLE1 described experiencing homelessness and being at risk of losing his leg due to cold weather before availing of medical attention. BIHLE5 claimed the care he received after leaving the military was much superior in Croatia than in Bosnia. BIHLE5 did not have a unique experience of discrimination based on military service. The Republic Srpska had limitations on the entitlements of veterans who served for armies other than their

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\(^{872}\) Access and Knowledge, Inclusion and Participation are cited as the outcomes by Lorna Jean Edward’s report into disability in the context of development. *Ibid*
own in the aftermath of the war which has been highly detrimental to populations who returned after ethnic cleansing.

BIHP5 describes the obstacles facing organisations representing and advocating for persons with disabilities: *There are some attempts. The thing is that the disability movement is quite segmented, as is everything else. The country is divided so the disability movement is divided and then also the competence of different levels of government will be different.*

The first disability specific information centre, LOTUS, was established in BiH in 1997. This organisation initially promoted disability issues alongside other mainstream human rights issues and representation in the community and has evolved to incorporate support for independent living in its work. LOTUS has established Centres for Independent Living in projects funded through international aid. The International Federation of Persons with Physical Disability highlight the momentum during and after the war to establish organisations of, and for, persons with disabilities. Its report describes how civil society and voluntary organisations established norms and benchmarks and worked to pilot successful programmes in order to fill a gap in disability service provision.

Disability services in the aftermath of the conflict followed a similar structure to the pre-war era with services available based on individuals’ perceived social contribution, and source of the disability, rather than individualised support to live independently. In this sense, the source of the individual’s impairment influenced the degree and type of supports, including financial assistance, available to them. More beneficial treatment was afforded to war veterans than to civilians injured in the conflict, who in turn received better conditions than those with a disability not connected to the conflict. Memisevic et al indicate that persons

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875 Ibid.
877 Hope 87 provides rehabilitative services for persons injured through mines and conflict. Despite being directly connected to the conflict the non-veteran status would result in less social assistance being available. <http://www.hope87.at/gallery/bosnia-and-herzegovina-support-persons-disabilities> accessed 15 January 2018.
878 An individual’s potential to contribute through employment or service to the community was central to how they were perceived and how supports were organised. If an individual acquired disability through military service or while engaged in activities for work they were treated more favourably than those with intellectual disabilities.
with intellectual disabilities therefore continue to experience the lowest quality of life within the category of persons with disabilities in BiH\textsuperscript{879}.

BIHP1 explained how the inherent inequality of the social protection system is reinforced by legislative provisions within each of the entities that determine eligibility criteria separately. Within BiH, individual cantons determine eligibility criteria for social protection. Within the Federation of Bosnia Herzegovina, additional financial assistance to a baseline allowance is available based on the degree of disability in accordance with the Law on Social Protection first introduced in 1999\textsuperscript{880}. In the Republic Srpska the additional allowances are meagre and are linked to availing of a carer or support person\textsuperscript{881}. BIHP1 was critical of these differences in support throughout the country and of the categorisation of support need being linked to the perceived source of the individual’s impairment.

BIHP1: \textit{In terms of where people live, in terms of them having different rights, not equal rights. What is the cause of disability? Whether it is war or not, civilian victims of war or not, it is not defined. If we take that into consideration there are three different groups of disability. Civilian victims of war – they have the best. The first one isn’t civil – it is people who become disabled in the war like soldiers – military. Second group is civilian victims of war. Third group is those who have nothing to do with the war and they have the worse status and we see they have direct discrimination.}\textsuperscript{882}

In 2003 there were eleven day-care facilities for persons with ‘mental handicaps’ in the Federation of Bosnia Herzegovina and ten more general social protection institutions accommodating the elderly and children in the Republica Srpska\textsuperscript{883}. These included both day services and residential services.

4.5 Section 4: Post UNCRPD Ratification (2010 – Present)

This chapter will now discuss the legislation, policies and commentary on disability services in BiH since ratification of UNCRPD.

\textsuperscript{881}Ibid
\textsuperscript{882}Extract from interview with BIHP1, 4 May 2016, transcripts on file with researcher.
4.5.1 Ratification of UNCRPD

BiH ratified the UNCRPD on March 2010⁸⁸⁴. Shortly after this, the Bosnian Minister for Disability⁸⁸⁵ responded to a Human Rights Council resolution pertaining to persons with disabilities⁸⁸⁶. This response outlines the role of the Civil Affairs Ministry in the development of inclusive disability policy and its mandate to coordinate efforts to promote the rights of persons with disabilities. The Bosnian Council of Disability was established in October 2010 as an initiative to discharge the duties of UNCRPD by the Council of Ministers in accordance with Article 33 of UNCRPD⁸⁸⁷. However, a review of Bosnia’s progress towards EU membership in 2012 noted that implementation of disability and social protection laws were weak and ineffective⁸⁸⁸.

BIHP3 laments the lack of resources provided to the Institution of Human Rights Ombudsman.

BIHP3: They don't have enough influence, they are not engaged heavily. They are concerned, they do pay attention to it but it is not a top priority that is what he is saying. So disability policy in general is a priority of organisations like (disability service organisation), not of the institutions of human rights……So they are seriously tackling the issues of persons with disabilities, she knows that for certain. They are monitoring the ratification and implementation of the UN Convention. They are advocating and conducting advocacy campaigns for persons with disabilities and their rights but she can’t claim for certain whether social policy is their top priority.⁸⁸⁹

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⁸⁸⁵ Minister of the day at the Department of Human Rights, Bosnia and Herzegovina.


⁸⁸⁹ Extract from interview with BIHP3, 6 May 2016, transcripts on file with researcher.
4.5.2 Current disability legislation and policies

At a national level, the Ministry for Civil Affairs is responsible for coordination of all social services and the Ministry for Human Rights and Refugees monitors domestic compliance with international human rights law. Within each entity – FBiH and Republica Srpska the obligation for the organisation of social services is further divided across cantons and municipalities as discussed earlier. The cantons and municipalities wield the power individually to decide levels of social welfare payments and the organisation of social services depending on the resources available to them. The obligation to adhere to non-disability specific conventions at a national level can serve to further the right to independent living for adults with intellectual disabilities in the absence of a coherent and comprehensive national framework legislating for the same.

The Law on Professional Rehabilitation and Employment of Persons with Disabilities includes persons with intellectual disabilities and provides for assessment of support needs and the allocation of funds for ensuring accessibility to places of employment and rehabilitation services including sports venues. BIHP1 references this legislation as he outlines the lack of disability exclusive legislation:

BIHP1: There aren’t many laws that exclusively apply to persons with disabilities. There is only one law. The Law on professional and rehabilitation and employment of persons with disabilities. Laws on social protection are important as well, health care laws, and education laws. Those are some key areas that concern people with disabilities. Laws on construction and environment, space orientation.

The Institution of Human Rights Ombudsman, the NHRI in BiH, has collated information on the most recent laws pertaining to persons with intellectual disabilities. Within the Institution of Human Rights Ombudsman is the Department for Following of Persons with Disabilities Rights. This department can receive and register complaints of violations of the rights of persons with disabilities including violations of dignity, equality and participation in

890 See Section 4.1.1.
892 Email correspondence with Institution of Human Rights Ombudsman for Bosnia Herzegovina, the National Human Rights Institution. Further they indicated that laws are only available in the local language. 17 August 2017, on file with researcher.
The Law on the Protection of Persons with Mental Disorders in the Republica Srpska established the Commission for the Protection of Persons with Mental Disorders overseeing the implementation of the protection of persons with mental disorders within Republics Srpska. These monitoring bodies govern different region but provide the same function.

More recently provision has been made for personal assistance for persons with disabilities, housing supports, a form of food aid and support to transition from institutions in the Republica Srpska through the Law on Social Protection 2015. This represents some positive progress towards addressing the shortages in practical facilities and commodities connected to under-developed community based services.

The only policy referenced to by the professional group of interviewees was the Equalisation of Opportunities for Persons with Disabilities Strategy 2011-2015. BIHP1 was very critical of this Strategy.

What would you say are the key reports or policies?

BIHP1: Strategy for equalization of opportunities for persons with disabilities. One of the key documents is two of these strategies in two entities. They are valid from 2011-2015. They are not valid anymore. A research on the implementation of those two strategies was conducted and it has been concluded that it was not implemented in a proper way. Mostly the activities were implemented but the goals weren’t implemented.

There is no doubt that Bosnia is aware of and engaged with the international human rights monitoring processes despite significant delays in meeting their reporting obligations. The internal human rights structures – the formal Institution of Human Rights Ombudsman and informal civil society groups - are consistently cited by UN treaty bodies as requiring increased resources. Concluding Observations by UN treaty monitoring bodies repeatedly urge the state to fully implement the recommendations of civil society organisations. Bosnia consistently is noted by UN treaty monitoring bodies to be failing in its obligations to respect

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894 Official Gazette of the Republic of Srpska’, No. 46/04.
896 Extract from interview with BIHP1, 4 May 2016, transcripts on file with researcher.
human rights across multiple themes of gender, economic, social and cultural rights that also impact persons with intellectual disabilities’ right to live independently. This is reflected elaborated upon by some of the participants in the qualitative research. For example, BIHP5 was critical of the lack of consideration given by government to the requirements for meaningful compliance with new international human rights laws. She noted that even with examination and feedback from the numerous monitoring bodies there is inertia in delivering on the government’s obligations.

The Annual reports from the Institution of Human Rights Ombudsman provide interesting information on complaints it has received from the public concerning disability rights violations. In 2016, 54 complaints were received in relation to inaccessibility, delays and difficulty accessing disability benefit payments and discrimination. These issues were unchanged from those reported in 2015 to the NHRI. As a National Human Rights Institution, the ombudsman is permitted to submit a report to the Committee on the Rights of Persons with Disabilities regarding the state adherence to its UNCRPD obligations. The Institution of Human Rights Ombudsman criticised the non-availability of disaggregated data on disability which could assist in developing indicators to monitor compliance with UNCRPD. This is in large part due to the refusal of the Republica Srpska to recognise and participate in a national census so it is clear that remnants of the conflict sill affect current governance structures. The Institution of Human Rights Ombudsman made a recommendation which is not compliant with UNCRPD. It suggested adjusting the legislation for placement in institutions so it is utilised in only limited cases. This would include where individuals have no family support systems and reflects the gap in reality of persons who are dependent on institutions and the states failure to provide the necessary pre-conditions for community living. Guidance from the Committee on the Rights of Persons with Disabilities prohibits institutionalisation of any kind as it does not facilitate choice and control over where and with whom one lives. As was discussed earlier, these conditions are within the remit of each

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899 This is a similar experience in other states and was echoed by the NI professional participants also. All of the NI Professionals suggested that the State has not fully considered the resource and investments required to deliver UNCRPD compliant independent living services.


901 Ibid

902 Ibid
individual canton so ultimately the decentralised nature of the state is a direct contributing factor to the state’s continued non-compliance with Article 19.

The FBiH has developed a 2016-2021 Strategy for the advancement of rights and status of Persons with Disabilities\textsuperscript{903}. BIHP\textsuperscript{1} is hopeful that it will be better enforced than the 2011-2015 Strategy for Equalisation of Opportunity:

Is there anything happening in the future to make things better, any government plan?

BIHP\textsuperscript{1}: The plan already exists [as of May 2016]. The government has a plan but nothing has been implemented or realized yet. The new strategy on disability is the main government which should last from 2016-2020. Persons with disabilities as representatives are also participating in the creation of that strategy.

Did that happen for the 2011-2015 strategy?

BIHP\textsuperscript{1}: Yes but it hasn’t achieved its goals, the previous one. He hopes that this strategy will be more successful. That it won’t share the same fate as the former one.\textsuperscript{904}

The FBiH have initiated a 2014-2020 Strategy for de-institutionalisation and transformation of social welfare which mandates that funds issued for institutional living to be dedicated to de-institutionalisation. Conversely, the 2014 Republica Srpska financial investment in social protection institutions far exceeded the allocations for in-home assistance\textsuperscript{905}, contrary to the requirements of Article 19 UNCRPD.

4.5.3 Civil Society Reports

The initial state report to the Committee on the Rights of Persons with Disabilities was due in 2012 but was not submitted until 2015\textsuperscript{906}. Before this occurred, civil society groups prepared

\begin{itemize}
\item Strategy for the Advancement of rights and status of persons with disabilities in the Federation of Bosnia Herzegovina 2016-2021. \\
\item Extract from interview with BIHP\textsuperscript{1}, 6 May 2016, transcripts on file with researcher.
\item Strategy for the Advancement of rights and status of persons with disabilities in the Federation of Bosnia Herzegovina 2016-2021. \\
\texttt{<http://www.fbihvlada.gov.ba/file/strategija1/Strategy%20for%20advancement%20of%20rights%20and%20status%20of%20persons%20with%20disabilities%20in%20the%20Federation%20of%20Bosnia%20and%20Herzegovina%20(2016-2021).pdf>}, accessed 6 November 2017. 18\% of social protection budget is allocated to institutions while only 1\% is provided for in home supports. It is unclear to what extent the populations availing of the institutions and home supports are persons with intellectual disabilities but the monetary allocations are still indicative of being in violation of Article 19.
\item This will be discussed further below at Section 4.5.5.
\end{itemize}
a report on the implementation of UNCRPD in 2014\textsuperscript{907} offering their evaluation of the state performance and potential for improvement. It combined desk based research on the legislative and policy framework, interviews with people with disabilities and examination of the portrayal of persons with disabilities in the media. The report asserts that the failed refugee return policies and separate Republics Srpska has led to divisions of disability services along ethnic lines and which is reinforced by the Dayton Accords\textsuperscript{908}. This exacerbates the lack of national oversight of the rights of persons with disabilities. Public awareness and attitudes which could generate social movements have not been addressed and where there are regulations on disability rights, the report states that no resources have allocated to ensure full implementation\textsuperscript{909}. The lack of accepted understanding of disability domestically and across legislation and policies was criticised in this Alternative Report. In relation to issues impacting independent living, the report also highlighted the non-accessibility of transport, the built environment, information and technology for persons with disabilities\textsuperscript{910}. The report noted that while NGOs do address this gap to some extent there is little, if any, coordination with the relevant statutory agencies to deliver resources for community living and the process of de-institutionalisation.\textsuperscript{911} Civil society suggested the Committee question the state on the financial commitments for the transition to community living and whether there will be regulation of support services for independent living. BIHP1 was of the opinion that the Alternative Report was rightly critical and countered the perceived inaccuracies of the state’s report,

BIHP1: \textit{They are meaning to say what the country hasn’t completed. The country is claiming it has implemented things that it hasn’t, they are making false promises and false claims.}\textsuperscript{912}

This report is extremely useful as it was completed shortly after UNCRPD ratification and demonstrates the lack of implementation by the government at that time. This also reinforces BIHP5’s statements on the role of international human rights law in Bosnia.

BIHP5: \textit{They are always the first ones to ratify any new human rights instruments and they


\textsuperscript{908}Ibid, pp10-13.

\textsuperscript{909}Ibid at p. 17.

\textsuperscript{910}Ibid at p. 21.

\textsuperscript{911}Ibid at p. 20

\textsuperscript{912}Extract from interview with BIHP1, 4 May 2016, transcript on file with researcher.
were the second country that ratified the optional protocol to the ICESCR. Which was like why would you do that, which tells you how quick they are to, like the Istanbul convention on violence against women. They are always the first ones to be there, to sign, to ratify. The parliament are very quick to react. It is really funny for me to see all these discussions in Ireland about UNCRPD ratification, I mean seriously people, in Bosnia they just go and sign off and do nothing. So it is really paradoxical seriously. They do submit their periodic reports and they get their concluding observations and they do nothing.913

The important role of civil society actors since UNCRPD ratification is highlighted again in the South East Europe Disability Monitor Report914. This report addresses general disability issues rather than intellectual disability specifically. Accessibility of buildings and public spaces is highlighted as a primary barrier to inclusion and while there are some examples provided of effective lobbying to link accessibility to public procurement contracts915 these obligations are not fully executed916. The significant differences in wealth of the cantons within Bosnia is also highlighted as a contributing factor in the lack of consistent implementation of disability laws917.

The Union of SUMERO918, a disability focused non-government organisation, have identified legal capacity legislation as a significant obstacle to achieving independent living for persons with disabilities in BiH919. Parent organisations have stepped in to address the gaps but parents tend to focus on the situation of their family member920. While this reflects the experience in other countries where parent and family organisations are active in calling for the rights of persons with intellectual disabilities to be respected, it would be more in keeping with the principles of the CPRD for adults with intellectual disabilities to form their own independent advocacy organisations to defend their rights.

913 Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
915 Ibid at p. 64.
916 Ibid at p. 77.
917 Ibid at p.78.
918 SUMERO is a union of service providers for persons with intellectual disabilities. Balkan Inclusion, <http://www.balkan-inclusion.info/about-us/sumero.html> accessed at 20 May 2014. SUMERO were also referenced by the Institution of Human Rights Ombudsman in correspondence.
920 Ibid at p.7.
Discussing the post-war social protection system in BiH, UNICEF highlight that there is no institution at state level responsible for social protection. As discussed above, the decentralisation of governance at the Federation level was very complex. UNICEF points out that there were more centralized social protection services, especially in relation to children with disabilities, in the Republica Srpska but despite this, international aid organisations still had to pilot social protection projects. Milosavljevic indicates that the current social protection system in FBiH, under which disability services are provided, is based on an ethos of helping, rather than addressing the causes of disabling factors in society. A review of BiH’s progress towards EU membership in 2012 noted that implementation of disability and social protection laws were weak and ineffective.

Centres for Social Work continue in the post-war period to be the mechanisms through which disability services are organised at municipal level and the lack of consistency among these bodies across municipalities and cantons is problematic in realizing the rights of persons with disabilities. This is not just confined to the delivery of disability services. Stubbs suggested in 1999 that international aid actors also organize their work in a largely geographically divided way. He argues that this is ineffective at properly representing interests at a national level and fails to influence policy. This provides further evidence of the segregated nature of social service provision under which supports for persons with intellectual disabilities would be delivered.

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922 See Section 4.4.
924 Ibid at p.10.
Continued institutionalisation is a fundamental violation of Article 19 UNCRPD. The Ministry for Health and Social work in FBiH is responsible for the organisation of social care institutions for persons with disabilities. Members of the Boards of Directors of these institutions are remunerated in line with the average wage. Their wages are provided for by the Centres for Social Work. The institutions are reliant on humanitarian aid, charitable donations, the charges for services and utilizing their own land for food. The lack of consistency across the institutions impacts on the accommodation, food, hygiene, employment and training facilities and this is further criticized by the non-transparency of appointment of directors and the vulnerability of the system to abuse.

The extent of the problem of institutionalisation was recognised by the Institution of Human Rights Ombudsman who published a report in 2009 on what they termed ‘Social Care Institutions’. This provides a comprehensive overview of the standards of institutions serving persons with intellectual disabilities and children. It provides information on the relevant legislation and policies and was completed through visits to institutions as well as interviews with staff and beneficiaries. The report highlights shortcomings in education, health protection, isolation from families and low standards of accommodation due to significant overcrowding. The lack of regard for the safety and mental health of both staff and service-users was also highlighted as a systemic issue. The report highlights that only two from the seven social care institutions in BiH are specifically designed for adults with intellectual disabilities. At the time of inspection in 2009, these two institutions had approximately 1,200 residents between them with 300 employees, the majority of whom had medical qualifications. Health services were available on site at both locations. Some sports and training activities were organized which included farm and agricultural work at one institution. However, at the second institution, investigators from the Institution of Human Rights Ombudsman found that 50% of residents did not have appropriate employment training or occupational therapy. Overcrowding was dominant in all of the institutions.

Conditions described in this report reflect the experience of BIHLE5 in an institution.

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930 Ibid at p. 51.
932 Ibid p. 17.
BIHLE5: [When he] came in institutions first of all he don’t have any activities. After ten years he get a workshop. (I told you about making slippers.).

So what did you do during the day when there was no activities?

BIHLE5: He went for the walk through the institution. Spoke with other people, beneficiaries of that institution and smoked cigarettes.

And what about food, did you feel you were well fed?

BIHLE5: Awful. He was given small amounts of food and it was awful.

And what about staff attitudes, were they nice to beneficiaries.

BIHLE5: All treatment was awful, food, staff everything. First ten years was more awful than other ten years. He was 20 years there. They changed directors of that institution often and every another director it was more awful. Another director it was not better treatment, [it became] worse.934

Later in the conversation I asked about inspections of institutions, as the Institution of Human Rights Ombudsman staff reported that on the day of their visit there was a cultural event organized by the residents themselves. BIHP4’s experience was that special efforts were made when external visitors came: Every time inspection came there all the whole staff were on their feet. All the rooms were clean, it was like a movie you know for that day.

Overall the Institution of Human Rights Ombudsman’s report recommended the need for investment in community based programmes, oversight of institutions and improve the standards within institutions. While the literature from international organisations, domestic human rights monitoring bodies and contributions from the qualitative participants indicated that social welfare infrastructure favoured institutionalisation during this period. The system was not responsive to individualised personal services but there was progress on national policies which attempted to reflect a human rights ethos. The ‘Disability Policy in Bosnia and Herzegovina’ was adopted in 2008. This was the first national disability policy which incorporated a social model of disability and has served as the benchmark for national policy since then935.

934 Extract from interview with BIHLE5, 3 November 2016, transcripts on file with researcher.
935 Government of the Federation of Bosnia Herzegovina, Strategy for advancement of rights and status of persons with disabilities in the Federation of Bosnia Herzegovina 2016-2021, Sarajevo, July 2016, at p. 8,
4.5.4 Current lives of persons with intellectual disabilities

Having examined legislation and policies related to disability services since the conflict the research will now consider the experience of persons with intellectual disabilities. The lived experience participants did not make reference to any policies or laws surrounding disability services so the relevance of these instruments in the daily lives of persons with intellectual disabilities seems minimal. The table below demonstrates the current living arrangements of the participants.

Table 14. Post Conflict living arrangements BiH.

<table>
<thead>
<tr>
<th>Living Arrangement</th>
<th>Institution</th>
<th>Independent service</th>
<th>Living</th>
<th>Family residence</th>
</tr>
</thead>
<tbody>
<tr>
<td>Gender</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>0</td>
<td>3</td>
<td>0</td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>0</td>
<td>1</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

BIHLE1 had experienced institutionalisation in the aftermath of the conflict and he said it was extremely helpful in facilitating his recovery and equipping him with independent living skills. Through the support of a local NGO he now resides with his girlfriend in the town where he was born which is important to him. He avails of a personal assistant and is confident that he has choice over who is employed in this role. However, he is not satisfied with the treatment of persons with disabilities in general and recognizes that he is fortunate in the supports available to him.936

BIHLE1: They don’t respect as they should, on all sides – Muslim, Serbian, Croatian, he believes that should be better. That is not on the way it should be. People are often left on their own, they don’t receive their exact support...All services are not on disposal of all people with disabilities. For example in this canton they have just a couple of, a few flats like this, so people don’t have access to live the way he is. There should be more services to


936 Extract from interview with BIHLE1, 7 May 2016, transcripts on file with researcher.
support people in a way to work. [His girlfriend] was just reminding him that there is one
guy in wheelchair and how the services are not accessible for him. So even there are services
in local community that he can’t use because they aren’t accessible – theatre, whatever.
There are some people who can’t even eat on their own. But they have these nurses who are
helping them to eat, they are supporting these people.

None of the participants with disabilities interviewed in BiH are currently employed but the
reasons behind this are varied.

BIHLE4: She never worked. She thinks she’s not capable of work. Her parents never thought
she needed to work because they always had the money to support her. Her mother gives her
allowance. Buys her everything basically.

Would you go into town by yourself?

BIHLE4: She comes here by herself. And she comes back, sometimes she comes with (friend),
sometimes by herself. She sometimes goes shopping by herself. But when they buy groceries
for the house, then she goes with her parents…..She always received nice treatment from her
hair dressers, the staff.

Having experienced childhood institutionalisation and being reliant on social protection
payments, BIHLE5 only engaged in minor repair work to earn some money before his second
period of institutionalisation as an adult. He asserted that he is willing and interested in
gaining employment in the near future but is prioritising adjusting to independent living.

BIHLE5: He don’t have a job right now but he wants to get a job.

Yes, what would you like to work as?

BIHLE5: Anything legal for money. (Laughing) Ah, and do you think that through (disability
organisation) you might get training to do that? When he was in institution in [town] he
wanted to get back to his local community [town] so he is pretty happy just being in [town]
so for job he will wait.937

Similarly BIHLE2 indicated that while he is currently unemployed he has had work
experience in a variety of roles but is interested in re-joining the labour market.938 His support
person contributed that this would be the mind-set of the majority of service-users supported

937 Extract from interview with BIHLE5, 3 November 2016, transcripts on file with researcher.
938 Extract from interview with BIHLE2, 9 May 2016, transcripts on file with researcher.
by this organisation.\textsuperscript{939} This could indicate a lack of investment in support and training for adults with intellectual disabilities to engage with the workforce in their communities.

BIHLE2 is also availing of supported independent living and attends an advocacy group which creates arts and crafts for sale locally. When asked initially about engaging with the community he responded with information on medical services but later mentioned more social activities. The conservatism that restricted BIHLE3 in her youth continued through adulthood and after marriage as she never engaged in formal employment but provided assistance to neighbours and conducted her domestic chores daily\textsuperscript{940}. BIHLE3 is the only participant to have gotten married and have a child. The marriage broke down in recent years and she experienced hospitalization intermittently\textsuperscript{941}. She described the unhappiness in her marriage compared to the relationship with her parents.

BIHLE3: \textit{When it comes to her life with her parents she says that she is mostly satisfied with it. Her parents always supported her, gave her enough money, they took care of her. They were loving and caring parents. But when it comes to her husband, in the first period of time she was satisfied to a certain extent but after that the situation got worse. Her husband was an alcoholic. She says she also had problems with her neighbours. They threatened her, I guess the neighbours were prejudiced and they threatened her. I guess they noticed she was a person with a disability and her husband as well with post-traumatic stress disorder so they weren’t very friendly.}\textsuperscript{942}

The hostility of the neighbours could be indicative of prejudices against persons with intellectual disabilities but that since intervention from the Centre of Social Work she is happy living independently frequently seeing her daughter and engaging in activities which she enjoys.\textsuperscript{943} She is positive about her future.

BIHLE3: \textit{She says she has it all. She says she has everything she needs. Basically in terms of food, all sorts of food she likes. If she wants ice cream, if she wants cake. She likes to cook. She was making rice. Everybody else was enjoying her last meal. She was, that was really socially unacceptable behaviour when she came here. When she got depressed she forgot all}

\textsuperscript{939} Ibid
\textsuperscript{940} Extract from interview with BIHLE3, 9 May 2016, transcripts on file with researcher.
\textsuperscript{941} Ibid
\textsuperscript{942} Ibid
\textsuperscript{943} Ibid
about making food, preparing food. But now she is getting better. She is restoring some of her old habits. She also likes flowers.

That's good!

BIHLE3: *She tends the flowers.*

And do you see your daughter now?

BIHLE3: *Her daughter comes to visit every day. She goes to school nearby so she can come to visit whenever she wants.*

And do you think you and your daughter will live together again?

BIHLE3: *Perhaps if they were able to find some apartment where the two of them could live and she would really like that. She says that she is satisfied with the disability services that are being provided to her at the moment.*

All of the participants with disabilities interviewed in BiH were aware of the existence of the UN Convention on the Rights of Persons with Disabilities and this was through the information provided to them through a local NGO. Connection with local NGOs has improved the quality of life of the participants and facilitates social interactions with their communities. It is clear that progress on independent living initiatives have been difficult to secure, varies regionally and there is lack of support for a co-ordinated approach across cantons from the State. The professionals referred only to a couple of national policies and were critical that resources had not been made available for to fully implement the policies. The participants in BiH described living situations which are largely compatible with Article 19’s choice and control over where and with whom to live. However, there are broader restrictions which disability services cannot address such as accessing the community which requires investment in public services.

**4.5.5 Universal Periodic Review**

During the most recent Universal Periodic Review of Bosnia Herzegovina in 2014 other UN member states had the opportunity to examine human rights broadly within the state. There are 33 references to disability within the Report of the Working Group on the performance of *Ibid*
BiH\textsuperscript{945}. These include positive comments about the development of a National Council for People with Disabilities to coordinate UNCRPD compliance\textsuperscript{946}. Comments on disability were made to BiH by states as part of comments on broader social justice issues including gender and ethnic minorities. The consensus was that while efforts were being made to improve the living situation for persons with disabilities these were yet to be effective. Finland highlighted the continuing differential treatment based on disability in BiH\textsuperscript{947}. The recommendations reinforced these criticisms and promoted actions by the State to ensure equality and inclusion of persons with disabilities in Bosnia Herzegovina.

4.5.6 Committee on the Rights of Persons with Disabilities

4.5.6.i State Report

Most recently the preparation of the State report for examination by the UNCRPD Committee has provided a broad overview of disability policies in BiH. The Initial Report from the State to the UNCRPD Committee refers to the better situation in Republika Srpska of community based services, although this seems to refer primarily to day services and supports. In relation to the FBiH, the State asserted that de-institutionalisation has been initiated and for those remaining in institutions there have been attempts to improve the quality of services. While not specified in the State report, the fieldwork suggests that younger persons with lower support needs have been prioritised in the de-institutionalisation process. The role of non-governmental organisations is highlighted as being very important in awareness raising and providing a multi-faceted approach to independent living addressing legal matters, accessible accommodation and transportation\textsuperscript{948}. In 2015 the Committee requested further information on the potential for a national deinstitutionalisation process\textsuperscript{949}. The State responded that the Republica Srpska has required that buildings for social housing and by use for the public must be fully accessible for persons with reduced mobility. The Republica Srpska is also in the process of drafting the 2016-2026 Strategy for Equal Opportunities for Persons with


\textsuperscript{946} Ibid at para 7.

\textsuperscript{947} Ibid at para 61.

\textsuperscript{948} Ibid.

\textsuperscript{949} Committee on the Rights of Persons with Disabilities, Consideration of reports submitted by states parties under Article 35 of the Convention, Initial reports of states parties due 2012, Bosnia and Herzegovina. \url{http://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2fPPrCAghKb7yhsuqSOFzP2VOfwcTgsJouflXTnao7E9uT2spIMqrM6alPE0emNNELLDiDZ10mlTdjY9a867M9pj6tWTfI2bs6oeibi7JNAKjaEREZRpViU%2bnKeU}

\textsuperscript{947} Ibid.
Disabilities which will have a dedicated section on deinstitutionalisation. These strategies were not referred to by the participants of the qualitative research which could indicate a lack of awareness and consultation with lower levels of government administration and civil society organisations on regional policies.

4.5.6.ii Concluding Observations

The Committee commended commitments by the state to increase funding and support for associations of persons with disabilities and the publishing of the 2016-2021 strategy. In relation to Article 19 specifically, the committee was critical of the high levels of institutionalisation and the continued investments in expansion and renovation of existing institutions as opposed to directing money towards independent living. It called for collaboration with disabled persons’ organisations in order to develop independent living services with a particular emphasis at the local and community level.

Alongside these specific remarks, the Committee was critical of the non-enforcement of anti-discrimination and disability equality laws. The difference in social benefit related payments based on the origin of disability. The need for increased awareness raising of the provisions of the Convention is referenced under Article 9. The Committee recommended reformation of the system of guardianship, which was also raised by some research participants linking it to institutionalisation and eligibility for pensions. There is a need for increased access to assistive technology enabling personal mobility under Article 20. Comments under Article 23, respect for the home and family, acknowledged the separation of

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950 This was referred to in Bosnia’s examination by the Committee on the Rights of Persons with Disabilities, at para 19.
951 Answers to the List of Issues in relation to the initial report of Bosnia and Herzegovina*, tbinternet.ohchr.org/Treaties/accessed/.../accessed_C_BIH_Q_1_Add-1_27187_E.doc, accessed 19 January 2018 at p. 15.
952 Committee on the Rights of Persons with Disabilities Concluding observations on the initial report of Bosnia Herzegovina, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) Para 34 and 35.
953 Ibid
954 Committee on the Rights of Persons with Disabilities Concluding observations on the initial report of Bosnia Herzegovina, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) Para 10-11.
955 Ibid
956 Committee on the Rights of Persons with Disabilities Concluding observations on the initial report of Bosnia Herzegovina, Adopted by the Committee at its seventeenth session (20 March-12 April 2017) Para 34 and 35.
957 Ibid
women with disabilities from their children, another aspect of relevance to living independently and being included in the community with families958.

4.7 Conclusion

BiH as a state has seen considerable change and transitions since the early 1990s. The war impacted everyone within the country and the qualitative interviews uncovered the involvement of persons with intellectual disabilities in the armed forces which had not been accounted for in any of the literature. The levels of disability services before the war were poor with lack of diagnoses contributing to worsening psychosocial disabilities in adulthood. Where a disability was diagnosed institutionalisation was provided if family support was not available, but no other supports were identified or offered. Where there was lower support needs families of persons with intellectual disabilities did not engage with state supports. The nature of information provision during the war for persons with intellectual disabilities was similar to that of the general community, if they resided in the community, but this was very low. Even participants who served in the armed forces reported having little knowledge at the time of causes of the conflict. For those institutionalised, it was suggested that there was no information provided about the circumstances and causes of the conflict. No participant reported ethnic tensions during their lives before the war and this contributed to the confusion regarding the causes of the conflict in the aftermath of the war also. There was a complete separation of the leaders involved in the Dayton Peace Accords from the citizens and efforts to return refugees to their places of origin and to establish disability services were weak and ineffective. The entity and cantonal levels of government are complex and are difficult for civil society to engage with in order to effect change. Institutionalisation occurs to this day and the NHRI research along with information provided by participants in the qualitative research and my own visit to an institution in the field provides strong evidence of the violations of basic human rights for persons with intellectual disabilities in BiH.

958 BIHLE3 was the only lived experience participant to have a family and encountered difficulties accessing appropriate supports to enable her to live with her daughter.
Chapter 5: Discussion and Conclusions
5.1 Introduction

Having examined the legislation, policies and qualitative research\textsuperscript{959} from NI and BiH individually, this chapter will now comparatively analyse these jurisdictions. The research discussed separately in relation to NI and BiH reveals that persons with intellectual disabilities have experienced the respective conflicts in unique ways. While some of their experiences align with that of the general population, their intellectual disability contributed at times to increased isolation and segregation from their communities, during periods in which solidarity and safety was restricted to those within ethnic communities. The qualitative research addressed gaps in the literature from both NI and BiH, pertaining to daily life, services, education, conflict experience and opinions on the peace process and UNCRPD which had not been captured previously. This makes the comparative analysis of findings a particularly original contribution to the field.

As discussed in the methodology chapter, the semi structured interviews in both jurisdictions followed the same format and attempted as far as possible to ask the same questions of both sets of participants. The discussion will combine a comparative analysis of the literature and qualitative research. This chapter will be arranged in accordance with the order of the research questions and the theme it aligned with from the qualitative research. The chapter will first recap the research questions and how it was answered. Next it will turn to the comparative discussion and finally it will outline recommendations for future action for compliance with Article 19 UNCRPD.

5.2 Emerging themes

The themes which emerged correlate to the research questions outlined in the methodology.

1. How were the lives of persons with intellectual disabilities impacted by legislative and policy measures governing disability services supporting independent living in the years immediately preceding the conflicts?

Chapter 2, Literature Review, detailed the historic rights violations experienced by persons with intellectual disabilities and the emergence of the Independent Living Movement in response to these violations. It outlined legislation and policies which resulted in recognition of independent living as a right of persons with disabilities in the UNCRPD. This literature review guided the desk based research for legislation and policies on independent living in NI.

\textsuperscript{959} The image at Chapter 5 title page is the Word cloud generated from NVIVO analysis of qualitative research.
and BiH and provided a benchmark against which to measure these states’ performances from the 1960s onward. However, this research question could not be fully answered by desk-based research alone. Qualitative research was undertaken to better understand the impact these laws and policies had on individuals’ lives. The contributions from the participants were coded using Clarke and Braun’s method of thematic analysis. The themes pertinent to this question were ‘life experiences’ and ‘services during pre-conflict.’

2. How were intellectual disability services impacted by the conflict and what were the experiences of persons with intellectual disabilities during the conflict in these states?

The desk based research provided details of the main events and actors of the conflict but there were no accounts of experiences of persons with intellectual disabilities or disability services in the existing literature for either jurisdiction. This data gap was noted by the professional participants and the research relied entirely on the qualitative research to address this gap in the data. The participant’s contributions were coded and the emerging themes were ‘life experiences’ and ‘services during period of conflict’.

3. To what extent were the rights of persons with intellectual disabilities to live independently considered in post-conflict societies during a period for state rebuilding?

The peace processes of each conflict received international attention and as such have garnered significant academic interest. The development of disability services by international aid actors in the aftermath of the conflict in BiH was well documented but this literature focuses only on services for physical disability. More legislation and policies pertaining to social welfare and the evolving nature of existing health services to recognise the rights of persons with disabilities was available in the desk based research in NI than BiH. Contributions from the professional and lived experience participants provided information on the implementation of the legislation and policies issued by government departments. These contributions were coded and the theme of ‘impact of peace process on disability

960 Discussed at Section 1.7.
961 Excerpt from interview with NIP1 and NIP2, 22 March 2016, transcript on file with researcher.
962 Discussed at Section 4.2.2.
rights’ emerged. The theme of ‘life experiences’ in the post-conflict era also related to this question.

4. To what extent have Northern Ireland and Bosnia Herzegovina complied with their obligation under Article 19 UNCRPD - to facilitate independent living and inclusion in the community for persons with intellectual disabilities?

The Literature Review in Chapter 2 has established the current norms of Article 19 through Concluding Observations963 and General Comment No. 5 from the Committee on the Rights of Persons with Disabilities964. Academics and civil society organisations have also contributed to the discourse on how best to realise Article 19965. The contributions of professionals provided detailed information on the perceived effectiveness and monitoring of national policies while the lived experiences group recounted the changes in their living circumstances since UNCRPD ratification. Along with ‘Life experiences’ the theme of ‘UNCRPD ratification impact’ addressed this question.

The research questions will now be addressed by comparatively discussing the research obtained on both jurisdictions.

5.2.1 Services during pre-conflict

Q1: How were the lives of persons with intellectual disabilities impacted by legislative and policy measures governing disability services supporting independent living in years immediately preceding the conflicts?

The literature and qualitative research suggests that the influence of legislative and policy measures on the lives of persons with intellectual disabilities depended on the extent of engagement with state provided services. In NI, the health and education system seemed more successful at identifying the presence of intellectual disabilities in children than in BiH. All lived experience participants in NI had received a diagnosis of intellectual disability during their youth. By contrast, only one participant in BiH had been diagnosed with an intellectual disability in childhood (Down Syndrome). In NI institutionalisation was not encouraged by the state during childhood but was a default in the absence of any support

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963 Discussed at Section 2.11.
964 Ibid
965 Ibid
systems. This is in sharp contrast to the literature and qualitative research in BiH which evidenced a state attitude that institutionalisation was preferable for persons with intellectual disabilities even where families were capable of providing support. In BiH the system of diagnosis for intellectual disability was ineffective and institutionalisation was encouraged upon diagnosis. The exception to this was where there was significant wealth and resources to access rehabilitation and extra curricular supports above what was available from the state. The literature and qualitative research also suggested institutionalisation was reverted to in BiH in order to address a wide variety of social issues – poverty, physical disability, behavioural issues and family status.

The forms of support for the participants varied from accessing specialised medical treatment in neighbouring jurisdictions to traditional family caring roles. Living arrangements during participants’ childhoods in NI and BiH spanned living with immediate and extended family. Across both jurisdictions six participants resided with immediate family and two resided with extended family. Two participants spent a significant period of their childhood in institutions. Segregated education in NI was the only type of support available during childhood referenced by the participants. The literature indicated that modest financial supports were provided in both jurisdictions but there was more focus on equipping persons with intellectual disabilities to contribute to the labour force in some way in BiH than in NI. The professional participants in NI described how day centre services for adults with intellectual disabilities first became available during the conflict. The literature highlighted that health and social services in NI were organised in line with those provided in the UK. The literature also suggested this was undertaken in order to avoid tactical investment or non-investment based on ethno-nationalist prejudices. The contributions from the professionals in NI indicate an elaborate, highly bureaucratic system that attempted to keep pace with developments in the delivery of services and to address the needs of the community.

NIP1 was the only participant to experience institutionalisation as a child in NI.

BIHLE5 was institutionalized despite family available to provide care. See interview on 3 November 2016.

BIHP5 also asserted that families were encouraged to place children with disabilities in institutions, 7 August 2016, transcripts on file with researcher.

BIHLE4 was placed in an institution due to behavioural issues which was an undiagnosed disability. See interview on 7 August 2016, transcript on file with researcher.

BIHP5 was originally placed in an institution due to behavioural issues which was an undiagnosed disability. See interview on 7 August 2016, transcript on file with researcher.

The literature highlighted that health and social services in NI were organised in line with those provided in the UK. The literature also suggested this was undertaken in order to avoid tactical investment or non-investment based on ethno-nationalist prejudices. The contributions from the professionals in NI indicate an elaborate, highly bureaucratic system that attempted to keep pace with developments in the delivery of services and to address the needs of the community.

Discuss at Chapter 3, Section 3.2.3.
served. Diagnoses of intellectual disability came through medical or health services in NI. While there were multiple legislative and policy provisions regulating the health and social services of both jurisdictions, these were not referenced in the qualitative research by professionals who worked in the sector at the time. This would indicate that staff on the ground were more directed by the needs of service-users and the available resources rather than rhetoric which had been devised without their input.

By contrast, disability services in the pre-conflict period in the former SFRY were much less structured. Broad provisions regarding social insurance and social institutions were enshrined in the Constitutions from the 1960s to 1980s. Services for persons with disabilities were provided at local level without oversight at a national level. This led to fragmented services across regions with disparities regarding geographic availability and quality. The medical model featured heavily with families being actively encouraged to place their children in the care of professionals within institutions who were deemed best placed to provide care, segregated from the community. The goal was to enable families to participate in the workforce by alleviating domestic caring duties. The system of diagnosis for intellectual disability was weak, with only the participant who had a disability identifiable from birth (down syndrome) having a diagnosis from youth. Her experience of availing of health services in another jurisdiction is also indicative of the lack of supports available in her own region. Where families did suspect the presence of a disability in rural areas, this was often not highlighted to local health or social services and the individuals remained supported by their families until adulthood.

The legislation in both countries affecting the lives of persons with intellectual disabilities in the pre-conflict era contained elements of the paternalistic and medical focus which...
characterised services of that era. Both jurisdictions were subject to international human rights law and were heavily influenced by neighbouring jurisdictions - primarily mainland UK and the USSR. However, the legislation and policies were never on a par with their neighbouring jurisdictions concurrently as progress was delayed in NI and BiH. There was a delay in recognition of the right to education for children with intellectual disabilities in NI compared to their counterparts in the mainland UK. Within the SFRY, BiH implemented institutionalisation to assist families to continue to contribute economically to their society as was the policy in USSR. Both jurisdictions had legislation on employment protection and rehabilitation for persons with disabilities but this was more prominent in BiH. No professional in NI and only one BiH professional referenced such programmes during this time period. The literature also suggested in BiH that persons with intellectual disabilities were supported to engage in sheltered employment with modest remuneration where possible but in NI social welfare was linked to compensation for not being able to access the labour market. While the Department of Health in NI had policy statements on improving the standards of day services, it acknowledged that these did not embrace providing training and employment for attendees.

Although the pre-conflict years in these countries coincided with the development of the Independent Living Movement in the US and Europe, no such social change reverberated there. Institutionalisation across both jurisdictions featured similar characteristics – limited educational opportunities were available, and participants experienced segregation from and limited access to the wider community. Both participants who experienced institutionalisation in NI and BiH, reported that living conditions were poor in these institutions. Laborious tasks such as cooking, cleaning and manufacturing products for sale were reported as required activities. The Bosnian account of institutionalisation indicated the difference in treatment of

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981 Chronically Sick and Disabled Persons (Northern Ireland) Act 1972 and Article 57, 1963 Constitution of the SFRY.
982 Discussed at Section 3.3.7, Section 4.2.4 and Section 4.2.5.
983 Discussed at Section 4.2.4.
984 Extract from interview with BIHP3, 6 May 2016, transcript on file with researcher.
985 Discussed at Section 4.2.3.
987 The 1990 'People First' was critical of the lack of educational development and training of attendees of day services, discussed at Section 3.3.11. Also Collins and Pinkerton highlighted the lack of general employment opportunities in NI during the late 1990s which would have made employment prospects for persons with disabilities even more difficult, discussed at Section 3.4.5.
residents and standards of cleanliness and activities when inspections were occurring\textsuperscript{988}. Religious organisations delivering disability services featured more prominently in NI than BiH.

There were mixed experiences of education among lived experience participants. All NI participants received segregated education for ‘special needs’ while in BiH only one participant had. NI had a better developed system for identifying need for targeted educational intervention as the participants referred to being moved from mainstream to special needs education. The limited availability of special needs schools in rural areas in NI was referred to which required the affected participants to travel outside of their local community\textsuperscript{989}. Participants in both NI and BiH were satisfied with their level of education, but participants in NI expressed dissatisfaction at being segregated from their non-disabled peers in school. The majority of the NI participants reported receiving education without distinction as to the religion or ethnicity of their fellow students. This is contrary to mainstream education in Northern Ireland at the time which was segregated along religious lines\textsuperscript{990}. Education was not segregated along ethnic or religious lines in BiH.

Leisure activities in both jurisdictions were described as limited and often correlated to domestic chores, particularly for the female participants. While a lack of recreational facilities would have been experienced by the entire population, persons with intellectual disabilities were denied opportunities for informal recreation due to their disability and exclusion from mainstream education in NI. By contrast, more participants availed of mainstream education in BiH and thus managed to maintain their social connections from education into adulthood\textsuperscript{991}. Overall the male participants in both jurisdictions were exposed to higher levels of education than their female counterparts. The BiH male participants generally received some form of vocational training\textsuperscript{992} and while the education in NI was

\textsuperscript{988} Extract from interview with BIHLE5, 3 November 2016, transcript on file with researcher.

\textsuperscript{989} NILE1 was sent to a ‘backward school’ in a neighbouring jurisdiction, NILE3 travelled by school bus up to 45 minutes away from her home and NIP2 suggested that travelling to another town would weaken ties with their own community and be difficult logistically for persons with intellectual disabilities and their families. Extract from interview with


\textsuperscript{991} BIHLE3 lamented the loss of her friendships and social connections when she was removed from education. BIHLE2 recalled having close friends who he would meet with after school. Extract from interview with BIHLE2 and BIHLE3, 9 May 2016, transcripts on file with researcher.

\textsuperscript{992} Extracts from interviews with BIHLE1, BIHLE2, May 2016 and BIHLE5, August 2016, transcripts on file with researcher.
segregated for people with ‘special needs’ it was more academically focused993. The academic paths of the female participants were less vocationally focused in both jurisdictions, with accounts of training in domestic chores both within institutions and in family settings994. Education was the only element of gender based differential treatment during the conversations on the pre-conflict years.

5.2.2 Services during period of conflict

Q 2: How were intellectual disability services impacted by the conflict and what were the experiences of persons with intellectual disabilities during the conflict in these states?

None of the participants with lived experience reported having an understanding of the causes of the conflict at the time in either jurisdiction, rather they have learned about it since then. The conflicts did however impact the life of every participant in the research and for some of the participants it continued to impact them to the present day. In NI some of the participants’ childhoods coincided with the early stages of the conflict. The nature of the Troubles involved paramilitary rather than formal military activity. There was scope for involvement by members of the public in violence, such as stone throwing, without being a member of a paramilitary group. These activities were a marked feature of youth involvement in the Troubles. While only one participant in NI reported engaging in this activity, the professional participants indicated that support services would have been organised for persons with intellectual disabilities who were susceptible to involvement in this sort of behaviour due to peer pressure. Only one participant in NI was availing of full time disability service support during the conflict and no one in BiH was in receipt of disability services during the conflict. Therefore the research relied entirely on the accounts of the professional participants to understand the impact of the conflict on disability services.

Professionals who had worked with disability services in NI during the Troubles offered insight into the complexity of organising day services for people with intellectual disabilities travelling across conflict flashpoints. However, the importance of travelling independently on public transport minimised reliance on segregated buses which were forced to take

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994 NILE1, NILE3, NILE4, April 2016 and BIHLE3 and BIHLE4, May 2016, all described learning domestic tasks such as cooking, knitting, sewing. Transcripts on file with researcher.
convoluted routes to collect as many people as possible across many conflict zones. According to the professional participants in this qualitative research, the impact of the conflict on disability services often depended on where adults with intellectual disabilities lived, the location of the service and the availability of transport options. While accessing personalised support to enter the community can be challenging for disability services generally, the Troubles prevented institutionalised adults from travelling through communities the general population could access, albeit exercising caution. Both professionals and lived experience participants reported that prejudices from the public in each jurisdiction restricted the access of persons with intellectual disabilities to services in their communities.

The qualitative research from BiH covered the situations of institutions and humanitarian aid which will be discussed separately. Professionals indicated that during this period in BiH any organisation which had been acting as a disability service altered their work to distribute humanitarian aid. Religious organisations were heavily involved in this work but according to the professional participants there was no religious or ethnic discrimination regarding the people they supported. International aid organisations supported local groups to deliver humanitarian aid on the ground and one participant suggested that certain institutions were able to offer local people surplus supplies. This was not substantiated by literature, and no other participants had this view, so this would not have been a feature of all institutions. In NI there were no references to humanitarian aid in either the literature or contributions from participants as the conflict did not create life-threatening shortages of basic supplies.

Institutions for persons with intellectual disabilities were sometimes purposely targeted during the conflict and some institutions were also damaged during the conflict in BiH. One participant in NI suggested that isolated instances of violence were targeted at disability centres and another indicated that threats of violence were made against disability

995 Extract from interview with NIP2, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
996 Discussed at Section 3.3.8.
997 Discussed at Section 3.3.9.
998 Extract from interview with BIHP1, BIHP2, BIHP3 and BIHP4, May 2016, transcripts on file with researcher.
999 Ibid
1000 Extract from interview with BIHP3, May 2016, transcript on file with researcher.
1001 Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
1002 Extract from interview with BIHP2, 6 May 2016, transcript on file with researcher.

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service staff members by the disgruntled family members of service-users\textsuperscript{1003}. Shortages of supplies affected institutions in BiH but the commitment of staff ameliorated the dangers to residents\textsuperscript{1004}. The impact on shortages of supplies and dangers from military bombardment was more prominent in BiH. Access to disability day centres was problematic as transport routes were disrupted and service-users had to travel through different communities to attend which posed dangers in NI\textsuperscript{1005}. As well as threats to safety from the conflict, the natural environment – the cold winter – resulted in the deaths of many people both within and outside institutions in BiH. Participants in the qualitative research indicated that there were no admissions to institutions during the war in BiH and persons with intellectual disabilities who had been living with their families prior to the conflict continued to remain in family settings in BiH\textsuperscript{1006}. Conversely in NI efforts were made to move towards community based services during the conflict and these had a modest impact on reducing numbers of persons with intellectual disabilities residing in hospitals and institutions. Prejudices from members of the community against men with intellectual disabilities who did not serve in the Bosnian armed forces were reported by participants as a societal pressure to join the military\textsuperscript{1007}. While this social coercion existed, it was unlike the manipulation reported by professionals in NI for persons with intellectual disabilities to participate in low-level paramilitary activities.

Male participants in both jurisdictions witnessed violence connected to the conflict, but in BiH this was more pronounced through their role in the armed forces. The male participants reported sustaining significant physical injury during the conflict and the medical care provided to them varied\textsuperscript{1008}. No injuries were reported by the NI male participants. The experiences of the female participants were more aligned in both jurisdictions. Daily activities continued but with restrictions on freedoms to move within their communities. Female participants in each jurisdiction had relatives either in the army or killed during the conflict\textsuperscript{1009}. Traditional gender roles were in place before the conflict and influenced the

\textsuperscript{1003} Extract from interview with NIP1, 22 March 2016 and NIP5, 4 April 2016, transcripts on file with researcher.
\textsuperscript{1004} Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
\textsuperscript{1005} Extract from interview with NIP1, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
\textsuperscript{1006} Extract from interview with BIHP4, 6 May 2016, transcript on file with researcher.
\textsuperscript{1007} Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.
\textsuperscript{1008} Extract from interview with BIHLE1, BIHLE2, May 2016, and BIHLE5, 3 November 2016, transcript on file with researcher.
\textsuperscript{1009} Extract from interview with NILE3, BIHLE3 and BIHLE4 April 2016, transcripts on file with researcher.
experience of the lived experience participants as the men participated in conflict to a greater extent and the women engaged in domestic chores.

5.2.3 Impact of peace process on disability rights

Q3 To what extent were the rights of persons with intellectual disabilities to live independently considered in post-conflict societies during a period for state re-building?

Both jurisdictions availed of financial and technical assistance from international bodies in the post-conflict period. In BiH this was focused on rebuilding of physical infrastructure and establishing basic services. In NI the focus was on community peace building and in the initial rounds of funding, organisations supporting persons with intellectual disabilities were successful in aligning their work with the funding streams. This included sport, arts and leisure activities aimed at persons with intellectual disabilities from both ethnic backgrounds. The organisation of disability services in NI remained the same as prior to the conflict. Five year policies for delivery of disability services were developed from the highest levels of the Department of Health and Social Services and these demonstrated the progression of language and attitude towards increasing the rights of persons with disabilities. However, participants in this research did not reference these policies which indicates that they were not communicated to the persons who they purported to serve.

Participants with lived experience in both jurisdictions accessed disability services during their adulthood more so than they had done in their youth. The professionals in NI suggested that the organisation of disability services in the post-conflict period further minimised the potential for consideration of persons with disabilities’ needs. Due to the ethnic tensions, services were organised across geographic areas which were composed of either Catholic Nationalist or Protestant Unionist communities. Because of this there were always small numbers of persons with disabilities and intellectual disabilities within each locality and therefore their needs were not reflected in the design and delivery of general public services to individual areas. This was reported by participants as an obstacle to accessing the peace funds. When the funding streams became more focused, the small population of adults

1010 Discussed at Section 4.4.
1011 Discussed at Section 3.4.6.
1012 Discussed at Section 3.3.
1013 Extract from interview with NIP1, 22 March 2016, NIP2, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
1014 Extract from interview with NIP2, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
with intellectual disabilities that projects proposed by disability services would impact was not recognised as adequate to be granted funding\textsuperscript{1015}. Persons with intellectual disabilities continued to experience institutionalisation and segregation from communities in both jurisdictions but more so in NI as institutionalisation occurred during adulthood for the male participants. When administration of services was re-established through local government in BiH the Dayton Peace Accords had created an extremely fragmented system with each canton delivering disability services of varying standards depending on regional economic and social factors\textsuperscript{1016}.

Across NI, the peace process created a shift in attitude to recognise the rights of all citizens. The peace process in NI was negotiated by politicians who were recognised and supported by their constituencies and the Good Friday Agreement was accepted in a referendum\textsuperscript{1017}. An alternative approach was undertaken with Dayton Peace Accords. The Accords brought an immediate cessation to the violence and conflict but no consultation with the public was undertaken\textsuperscript{1018}. There was a considerable shift towards monitoring human rights in both as the NI Human Rights Commission and Equality Commission and the Institution for Human Rights Ombudsman in BiH were established. The rights of persons with disabilities is under their remit. However, two NI professionals asserted that while Section 75 of the Good Friday Agreement recognising equality on a number of grounds, including disability, was initially viewed as a positive trend, this has become merely a tick box exercise\textsuperscript{1019}. A general duty to respect human rights applies across the entire civil service in BiH but it is not as clearly formulated as Section 75 in NI. Only one participant referenced the BiH equality duty while all of the professionals and one lived experience participant referred to Section 75 in NI. Both of these mechanisms are considered by the majority of participants to be lacking potential for any substantive change.

There was division among participants in NI on the political priority accorded to of disability rights in the post-conflict era due to the focus having been on the conflict over the last two decades\textsuperscript{1020}. However in BiH there was consensus that disability was low on the priorities of government along with other social issues. Whereas in BiH the level of state support

\textsuperscript{1015} Ibid
\textsuperscript{1016} Discussed at Section 4.3.
\textsuperscript{1017} Extract from interview with NILE1 and NILE2, 5 April 2016, transcripts on file with researcher.
\textsuperscript{1018} Extract from interview with BIP5, 7 August 2016, transcript on file with researcher.
\textsuperscript{1019} Discussed at Section 3.4.2.
\textsuperscript{1020} Discussed at Section 3.4.
available is determined based on how a disability is acquired, with preferential treatment if acquired through the conflict, in NI persons with conflict-acquired disability do not typically identify as a person with a disability\textsuperscript{1021}. The issue of disability appears to have been siloed from the discourse on victims of the Troubles\textsuperscript{1022}. Integrated services across conflict and disability would concentrate on acquired physical and psychosocial disabilities rather than intellectual disabilities in any case.

The peace process in BiH brought about an end to armed conflict and destruction of physical infrastructure. The process was not as democratic as that in NI with no vote to formally accept the Dayton Peace Accords by citizens in BiH. The research has highlighted the lack of affiliation that citizens had to the politicians negotiating the Dayton Peace Accords\textsuperscript{1023}. To date, the Peace Accords, and resulting legal instruments, including the Constitution, have not been translated into local languages, much less being available in Easy to Read formats for persons with intellectual disabilities\textsuperscript{1024}. The complicated system of administration across two entities and further subdivisions of cantons and municipalities resulted in fragmented services across all aspects of social support. Continuing discrimination by legislation in BiH was reaffirmed by the professional participants regarding the different rates of social benefit payment based on the type of disability with preference given to former military members who acquired their disability during the conflict\textsuperscript{1025}. The investment by the World Bank also focused on physical accessibility and rehabilitation and the legislation being drafted at the time along with evidence of increasing rates of institutionalisation of persons with intellectual disabilities indicates that their needs were neglected during planning of the post-conflict society\textsuperscript{1026}. Disability services had to be established from scratch in the aftermath of the conflict and that families played a considerable role in the development of these organisations. Dayton is blamed by the participants and criticised in the literature\textsuperscript{1027} for the persistent inefficiencies of government administration which directly affected the lives of

\textsuperscript{1021} NIP1 referenced the disconnect between policies serving victims of the Troubles whose injuries resulted in disabilities and persons with disabilities which were not acquired during the Troubles. Extract from interview with NIP1, 22 March 2016, transcript on file with researcher. Further, pps 5-8, Breen-Smyth M, ‘Injured in the Troubles: the needs of individuals and their families’, http://www.wavetraumacentre.org.uk/uploads/pdf/1397727238--WAVE-Executive-Summary.pdf, accessed 18 March 2018.

\textsuperscript{1022} Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.

\textsuperscript{1023} Discussed at Section 4.3.

\textsuperscript{1024} Discussed at Section 4.3.

\textsuperscript{1025} Extract from interview with BIHP5, 7 August 2016, transcript on file with researcher.

\textsuperscript{1026} Discussed at Section 4.3.1.

\textsuperscript{1027} Discussed at Section 4.4.
persons with intellectual disabilities immediately after the conflict. National Human Rights Institutions (NHRIs) were established in the aftermath of the conflict which continue to function today. There were mixed responses among professionals regarding the records of NHRIs in promoting disability rights in both jurisdictions. As the male participants in BiH had their military service end after the conflict the peace process had a more immediate effect on their lives than the female participants and similarly than the participants in NI. There was no gendered element to the experiences of the peace process for NI participants.

5.2.4 UNCRPD ratification impact

Q4 To what extent have Northern Ireland and Bosnia Herzegovina complied with their obligation under Article 19 UNCRPD - to facilitate independent living and inclusion in the community for persons with intellectual disabilities?

While progress has been made in the recognition of the rights of persons with intellectual disabilities in both jurisdictions, residential institutions remain in both NI and BiH. These are delivered through health and social welfare services and vary from large scale institutions with hundreds of residents, located significant distances from the nearest towns, to smaller group homes in more populated areas. The standards of housing and in institutions appeared to be consistent across NI but there were disparities in living arrangements based on the socio-economic situation of each canton in BiH. Both jurisdictions have policies in place which commit to implementation of Article 19 CRPD. The eminent policy governing disability services in NI is the NI Disability Strategy. Both the FBiH and Republica Srpska have long term policies which address the right to live independently and be included in the community. These are the Strategy for the Advancement of rights and status of persons with disabilities in the Federation of Bosnia Herzegovina 2016-2021 and the 2016-2026 Strategy for Equal Opportunities for Persons with Disabilities respectively. The State party also indicated a dedicated de-institutionalisation strategy within the FBiH in its report to the UNCRPD Committee. However there was no evidence of this in other literature or from the participants so its impact seems very limited. These policies were not referenced by any of the lived experience participants but a majority of participants across the jurisdictions indicated some awareness of the UNCRPD. This suggests that there is limited information on the ground in both jurisdictions on how

1028 Extract from interviews with BIHP3 and BIHP5.
1029 Discussed at Section 3.5.2.
UNCRPD is being implemented domestically. The professionals in both jurisdictions perceived UNCRPD to be well known among high level government officials\textsuperscript{1030}. Both jurisdictions ratified UNCRPD within two years of it being open to signature after undertaking efforts to develop compliant legislation and monitoring mechanisms\textsuperscript{1031}. While the policies and legislation discussed contain language that reflects the UNCRPD, the attitude on the ground in both jurisdictions regarding the effectiveness of UNCRPD has been largely negative. All of the professionals stressed that there is a lack of resources for implementation and monitoring of the well-phrased objectives contained within the main national policies which relate to principles of the UNCRPD.

In NI two participants were availing of residential disability services and they had indicated that they had not been given any choice or control over where and with whom they lived. They described living in groups with 10 or more residents, no choices regarding meals and mealtimes or opportunities to participate in meal preparation having restrictions on their daily activities. This does not conform to the principles of Article 19 UNCRPD. The participants who resided with their families described greater levels of freedom but were very reliant on ageing relatives to access the community which is not sustainable in the long term. Only one participant in BiH described a situation of reliance on family whereas all of the other participants were residing in houses with choice and control over their housemates. One resided with a partner and the remaining three lived with either one or three other people with disabilities. They indicated having choice over their housemates and participating in household activities such as cooking, baking, gardening and cleaning. They also described being satisfied with their personal assistants and were comfortable that should an issue arise with their assistant it would be resolved.

Participants with lived experiences in both jurisdictions have been made aware of the UNCRPD through independent advocacy groups and their own interest in current affairs guided the extent of their knowledge. Two of the five NI participants’ current living arrangements which were provided by the State were not Article 19 compliant in NI. All participants in Bosnia Herzegovina were currently living arrangements which comply with

\textsuperscript{1030} Extract from interview with NIP5, 4 April 2016 and NIP3, 30 March 2016. They indicated that there is awareness of UNCRPD among high level government department staff and ‘official-dom’\textsuperscript{1030}.

\textsuperscript{1031} Northern Ireland Policy on Social Inclusion on Disability Working Group 2004 and the allocation of the BiH Civil Affairs Ministry and the Bosnian Council of Disability was established in October 2010 as an initiative to discharge the duties of UNCRPD by the Council of Ministers in accordance with Article 33 of UNCRPD. Discussed at Section 4.5.1.
Article 19 although for some the transition to living in the community was very recent. Civil society organisations are attempting to educate persons with intellectual disabilities about their rights and equality in both jurisdictions within the post-conflict context. The professionals in NI consider that these activities have been underdeveloped due to the incorrect perception that persons with intellectual disabilities are not capable of holding political beliefs or having political affiliations\(^\text{1032}\). The general population in NI has availed of multiple initiatives to increase human rights and equality awareness and eliminate sectarian prejudices which have not been available equally to persons with intellectual disabilities\(^\text{1033}\). The non-segregation of disability services along religious and ethnic lines supported the view of service providers that persons with disabilities would not need to have their ethnicity and religion catered to in a segregated manner in the same way that education, housing and other social services were provided for the general population at the time. Segregation for special needs education was the only educational segregation reported in BiH. BiH participants indicated that they could spend their childhoods alongside friends and neighbours from different ethnicities without issue. The only exception was the conservative religious attitude towards women in one particular case which restricted BIHLE3 from engaging fully with her community. This gendered restriction on community engagement was not experienced in NI.

The majority of the BiH professionals indicated frustration with a national government which ratifies international human rights treaties, including UNCRPD, without undertaking sufficient research and preparation as to the delivery and cost of adhering to their obligations. The qualitative research suggested that progression of disability rights and funding to support independent living is largely dependent on the interest of the individual office holders\(^\text{1034}\). Three professionals in BiH also highlighted the violation of UNCRPD principles through laws which segregate education and differentiate social welfare benefits based on origin of disability. UNCRPD ratification has been used as a tool at cross-cantonal levels in BiH for

\(^{1032}\) Extract from interview with NIP2, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
\(^{1033}\) NIP2 and NIP4 spoke of Peace funding for which it was difficult to align the activities of disability services to grant streams. Extract from interview with NIP2, 22 March 2016 and NIP4, 4 April 2016, transcripts on file with researcher.
\(^{1034}\) BIHP2 claimed that while he was in a position of power in local government, considerable progress was made by his ministry which had responsibility for disability Issues in FBiH. There was opposition to his efforts to implement community-based living but he pursued it and established collaborative networks between civil society organisations on this issue. Extract from interview with BIHP2, 6 May 2016, transcript on file with researcher.
empowerment and education of families and staff of disability services and local government agencies. One participant in BiH suggested that while the UNCRPD has had little impact on legislation there have been revisions of cantonal strategies to reflect the principles of the Convention. While this is a positive aspect concerning UNCRPD implementation, the fact that there is no similar nation-wide initiative does suggest the limited impact of UNCRPD. One professional in BiH further suggested that the EU could have a role to play in pressuring the state to comply with all of its international human rights obligations.

The participants with lived experience in BiH were less familiar with UNCRPD than their NI counterparts but again had learned about it through their disability service. All of the participants in Bosnia were participating in independent living programmes at the time of the interviews and were very positive about their current living situation compared to that of the past.

5.3 Conclusion of comparative discussion
The research has addressed a gap in the literature on the experiences of persons with intellectual disabilities of the conflict in NI and BiH. Further research is needed in order to form a more holistic recognition of the experiences of all citizens and inform future independent living policies in NI and BiH. This research aimed to uncover common factors between the experiences in order to devise recommendations on how best to realise the Article 19 rights of persons with intellectual disabilities in the aftermath of a conflict. Six recommendations have been developed which have the realisation of Article 19 at their core but the inter-connectedness of all UNCRPD rights means other articles have also been identified as necessary to achieve Article 19. This chapter will now discuss the rationale for these recommendations which are summarised at the end of each section.

5.4 Recommendations for Article 19 compliant disability services in post-conflict countries

**Recommendation 1:** Public services (including education) to be inclusive across ethnicities and disability. This will fulfil Article 3, Article 5, Article 19 and Article 24 of the UNCRPD.

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1035 Extracts from interviews with BIHP1, 4 May 2016 and BIHP4, 6 May 2016.
Based on this comparative research, no disability supports in the pre-conflict years were integrated with mainstream public services in either jurisdiction. However, this was typical of disability services internationally and was what the Independent Living Movement sought to change. In both jurisdictions the role of families was crucial to avoiding institutionalisation and the support provided depended largely on their socio-economic resources. There was no reference by the participants with lived experience to supports for their families from the state in NI during their childhoods\textsuperscript{1036}. However, each participant engaged with some form of education during their youth and a social service during adulthood\textsuperscript{1037}. For the majority of Bosnian participants who had resided with their families they had no knowledge of institutions\textsuperscript{1038}. This would suggest that unless a person was connected to state supports in some manner he or she would not be exposed to state institutionalisation. This highlights the hidden nature of institutions from the general population at the time. Ethnicity per se did not feature as a discriminatory factor in the access to disability services during the conflict in either jurisdiction but the association of regions with an ethnic population or as an area of violence did pose difficulties in accessing disability services and supports. The reports from BiH and NI indicate that in general ethnic tensions do not pose disruption to accessing public services in the post-conflict era and this is in line with the experiences of the general population\textsuperscript{1039}.

Education which is integrated and inclusive of persons with disabilities and those of different ethnicities, religions and cultural backgrounds, is crucial to prevent unequal and discriminatory treatment of persons with intellectual disabilities. Participants in the lived experience groups were aware during their childhoods of the ethnic and religious background of their peers whether they were in segregated institutions or their general communities. No participant expressed having a problem with availing of services with people of different ethnicities but they disliked being segregated from the local communities, being marked out

\textsuperscript{1036} NIILE2 indicated that he was not aware of any services during his youth and the remaining participants did not reference childhood services at all when discussing their lives. See transcripts from NIILE1, NIILE2, NIILE3, NIILE4 and NIILE5, March and April 2016, transcripts on file with researcher.

\textsuperscript{1037} Ibid

\textsuperscript{1038} BIHLE2 was not aware of institutions during childhood and BIHLE4 was only familiar with them due to a friend having resided in an institution in the past. Extracts from interviews with BIHLE2 and BIHLE4, May 2016, transcripts on file with researcher.

\textsuperscript{1039} All of the BIH Professionals group made reference to the non-ethnic or sectarian nature of public services currently. Extract from interviews May and August 2016, transcripts on file with researcher.
as different and lacking choice and control over basic life decisions\textsuperscript{1040}. Implementing fully inclusive education for students from a young age exposes them to peers from diverse backgrounds and with varying abilities which will normalise everyday interactions with persons with intellectual disabilities for future generations.

The segregation of disability services and services for victims of the Troubles was also highlighted as a failure by the state. The cultural identities of persons with intellectual disabilities should be respected in line with the general population when planning and delivering disability services to ensure they are not excluded from their immediate communities. Similarly, any initiatives promoting peace which are focused on ethnic tensions must include persons with intellectual disabilities.

**Recommendation 2**: States must provide funding for and implementation of disability services which allow persons with intellectual disabilities to exercise choice and control over where and with whom they live, access to necessary support to realise their choices and participate fully in the community. This will ensure adherence to Article 19 UNCRPD.

There are very positive examples of Article 19 compliant public services being delivered in both jurisdictions included in this comparative study, but they are limited either by the resources of voluntary organisations or their geographic scope. These encompass health, education, employment, leisure and transport. The continued existence of residential institutions in NI and BiH violates Article 19. However, all of the participants with lived experience in the qualitative research, including those living in institutional settings, suggested that they were satisfied with their current living arrangements. The standards of residential services has improved since the conflicts have ceased but lack of choice and control over where and with whom to live prevails\textsuperscript{1041}. With adequate supports, all the participants could successfully exercise choice and control over where and with whom they live. Civil society organisations who are not financially supported by the State are engaged in providing supports for independent living in BiH whereas the statutory health service in NI partially contracts out and financially supports voluntary organisations to provide disability

\textsuperscript{1040} All lived experience participants in NI and BiH referred to segregation from the community as negative and not being prejudiced towards persons of different ethnicities. Extracts from interviews with NILE1-5, April 2016 and BIHLE1-5, May and November 2016, transcripts on file with researcher.

\textsuperscript{1041} NILE1 and NILE3 reside in institutions without choice over where and with whom to live. Extracts from interviews, April 2016. BIHLE5 had recently moved from an institution to the community and described conditions of the institution as lacking choice and control over where and with whom to live. Extract from interview with BIHLE5, 3 November 2016.
services. The accommodation provided by disability services accessed by the lived experience participants in BiH appeared to be more Article 19 compliant than those purported to be independent living for the lived experience participants in NI. Civil society organisations in BiH are funding these initiatives through international development donors to demonstrate to state actors that independent living can be achieved whereas in NI the State is limiting the potential for imaginative approaches to independent living by continuing to provide the majority of funding to residential institutions and traditional group homes. In NI direct payments have not been properly implemented and require significant expertise on behalf of the individual or their support network to ensure compliance with regulations. The levels of payment available were criticised as unrealistic and there was frustration that NI could not benefit from the experience of operationalising direct payments in mainland UK. Alternatively in BiH, an individual’s status as acquiring a disability through the conflict improves the social welfare and services available. This has the effect of further relegating persons with intellectual disabilities in the social welfare priorities.

The NI Disability Strategy articulates Article 19 compliant policies but its implementation has yet to be realised. Participants highlighted that realistic and measurable targets should be set for implementation and adequate resources allocated for their accomplishment. Both BiH and NI retain legislation which is not compliant with Article 12 UNCRPD so this should be rectified immediately. Being denied legal capacity can result in forced institutionalisation and having decisions on important life choices challenged or not recognised based on a paternalistic instead of individualised support approach. Addressing issues which affect the general population such as low quality infrastructure, poverty and regional inequality will also positively impact on the ability of persons with intellectual disabilities to live independently in both jurisdictions. In BiH specifically, the Dayton Peace Accords are perceived by participants in the qualitative research to be hindering the progress needed in the

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1042 Extract from interview with BIHLE participants, May and November 2016, transcripts on file with researcher. Participants described exercising choice over where and with whom they lived, receiving personalised supports and preparation for living in the community. NILE2, NILE4 and NILE5 merely continued their childhood living arrangements with family members without support for increased independence. Excerpts from interviews on April 2016, transcripts on file with researcher.

1043 NIP4 and NIP5 referred to the current bureaucracy in NI disability services while NIP1 and NIP3 referred to the lack of resources being made available as a contributing factor for non-compliance with Article 19. Excerpts from interviews March and April 2016, transcripts on file with researcher.

delivery of all social services and advancements in community living projects have only been made due to the personal interests of politicians\textsuperscript{1046}.

**Recommendation 3:** Include persons with intellectual disabilities in the development of laws and policies to resolve ethnic tensions and conflicts, and to develop support for independent living. This will facilitate realisation of Article 4(3) and Article 19 UNCRPD.

While people with intellectual disabilities in NI experienced the conflict in many ways similar to other people, they often reported increased limitations on movement and had less access than the general population to information on the conflict. The location of the participants in both jurisdictions determined the extent of the conflict which they were exposed to. The male participants experienced volatile and dangerous situations in the armed forces in BiH\textsuperscript{1047} while there were accounts of male youth involvement in minor to moderately dangerous situations in NI\textsuperscript{1048}. For all participants with lived experience in both jurisdictions the political reasons which brought about the conflict were not understood. The conflict forced some disability services to provide support for the wider general population in Bosnia\textsuperscript{1049} while the well-established disability day services and residential institutions in NI had difficulties in organising staff and experienced disruptions to transport for service-users and staff alike\textsuperscript{1050}. Human rights or disability rights did not feature in the discussion of the conflict in BiH but an attempted civil rights movement was the catalyst for the Troubles in NI. However, human rights ideals in Northern Ireland were linked to a Nationalist agenda and this rhetoric had the potential to undermine people who sought to create a unified disability rights movement across religious and political divides. It is partly for these reasons in NI, and the total survival mode of the population in Bosnia and surrounding states, that a disability movement such as that which had been organised in the US and UK could not come about at the time of the conflicts.

Overall, persons with intellectual disabilities were completely excluded from participation in the peace processes in both jurisdictions. There was no consultation with persons with

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\textsuperscript{1046} Extract from interview with BIHP4, 6 May 2016, transcript on file with researcher.
\textsuperscript{1047} Extract from interviews with BIHLE1, BIHLE2 and BIHLE5, May and November 2016, transcripts on file with researcher.
\textsuperscript{1048} Extract from interviews with NILE2, NIP4 and NIP5, March and April 2016, transcripts on file with researcher.
\textsuperscript{1049} Extract from interviews with BIHP1, 4 May 2016 and BIHP3 6 May 2016, transcripts on file with researcher.
\textsuperscript{1050} Extract from interviews with NIP1, 22 March 2016, NIP2, 22 March 2016, NIP4, 4 April 2016 and NIP5, 4 April 2016, transcripts on file with researcher.
intellectual disabilities in NI during the post-conflict period as contributions from participants with intellectual disabilities indicated lack of understanding about the substantive issues on which they were voting on contained within the Good Friday Agreement\textsuperscript{1051}. Attempts were made to re-establish disability services in BiH in the aftermath of the conflict\textsuperscript{1052}. None of the participants in NI reported changes in their living arrangements from directly before the conflict\textsuperscript{1053}. BIH participants who had served in the armed forces all experienced institutionalisation following the conflict. This was initially for medical treatment but the period of institutionalisation was extended due to their intellectual disability\textsuperscript{1054}. This indicates a regression of independent living services as the relevant local authorities could have established community based systems for rehabilitation and support of persons with intellectual disabilities.

A potential lesson for BiH from NI in the event of reform of the bureaucratic nature of the system of governance is the extraction of ethnic tensions from the delivery of health and social services. Health policies in NI did not reference regional preferences which would have resulted in ethno-nationalist discrimination\textsuperscript{1055}. No disparities in standards of health and social services in NI based on ethnicity reported during the conflict. There were admissions that a minority of service-users would refuse to attend a service based on its location and the majority ethnicity of the community\textsuperscript{1056}. Interestingly during the conflict in NI there were reports of tensions between staff and service-users of different ethnic backgrounds whereas in Bosnia during the conflict this was not so widely reported.\textsuperscript{1057} However, the post conflict situation in Bosnia has the state divided along majority ethnic lines with the differences in regional economic and social prosperity\textsuperscript{1058}. This impacts the availability of health and social welfare services to the general population. Professionals in NI criticised the state’s reluctance to include persons with disabilities in policy making processes post UNCRPD.
ratifications. BiH professionals described the inclusion of persons with intellectual disabilities and their families in the formation of regional disability policies post UNCRPD ratification.

Based on this research during periods of conflict all services which persons with disabilities would have normally accessed were disrupted on an equal basis with the general population, regardless of ethnicity. They were not excluded or exempt from the dangers and negative impact of the conflict but each state failed to recognise their capability for contributing to creating a post-conflict society which is inclusive for all citizens.

**Recommendation 4**: Include persons with intellectual disabilities in consultation on issues affecting their communities and wider society. This should include providing accessible information on changes to governance structures, delivery of public services, public awareness campaigns and utilising the justice system to remedy discrimination against persons with intellectual disabilities. This would address Article 5 (equality and non-discrimination), Article 8 (1) and Article 13 (1) of UNCRPD as well as Article 19.

There has been unprecedented upheaval in the current political climate of the UK with the decision to leave the EU which will inevitably impact NI. This is further impacted by domestic political stalemate within NI which has prevented the NI Assembly from operating. While the UK and NI’s obligations under the UNCRPD remain, the exit of Britain from the EU could alter the legal and structural mechanisms for delivery of disability services. Legislation and policies may not be subjected to such rigorous human rights analysis, nor goods and services be required to meet the safety and quality standards as previously required by EU provisions. This could affect persons with intellectual disabilities living independently who are availing of assistive devices or employing personal assistants.

At the other end of the spectrum, BiH’s candidacy for EU membership has the potential for greatly improving the availability of funds dedicated to independent living initiatives. Further, the applicability of EU standards and quality of goods and services should benefit persons with intellectual disabilities availing of assistive technology. The interviews indicated that the government is aware of the experience of neighbouring jurisdictions

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1059 Extract from interviews with NIP1, NIP2, NIP3 and NIP4, April 2015, transcripts on file with researcher.
1060 Extract from interviews with BIHP3 and BIHP4, May 2016, transcripts on file with researcher.
becoming EU members. While they are cognisant of problems arising from the process they remain committed to joining the EU but there will be an onus on the EU to demand adherence to legislation and regulation in order for a positive impact to be achieved on the ground\textsuperscript{1062}.

There were varying degrees of satisfaction among the lived experience participants in both jurisdictions in their interactions with members of the public in their local communities. For many of the Bosnian participants, their interactions remain confined to family and disability service and advocacy staff and peers. In NI, lived experience participants reported higher instances of interacting with the general community than in BiH and an awareness of how persons with different levels of support needs than themselves are served\textsuperscript{1063}. The female participants proved to be more sheltered from their communities than the male participants in both jurisdictions. Both professionals and lived experience participants suggested that while UNCRPD has resulted in increased visibility of persons with disabilities, including persons with intellectual disabilities, there is still progress to be made in this regard. Examples of reduced instances of bullying in NI were countered with resistance among state officials to include persons with disabilities in consultations and negative perceptions of persons with disabilities in the media\textsuperscript{1064}.

Public awareness, equality and anti-hate campaigns should be designed and implemented in which National Human Rights Institutions and Disabled Persons’ Organisations can have a role.\textsuperscript{1065} Civil sanctions should be enforced against organisations and individuals where actions against persons with intellectual disabilities are found to be discriminatory due to disability. NHRIs could exercise their amicus curiae or legal representation powers in litigation where access to goods, services, employment, or accommodation has been refused illegally on the basis of intellectual disability. Redress in the form of personal compensation and requirements to prevent discriminatory action in the future should be available to the individuals affected. In cases of violence and hate-crimes being committed against persons with intellectual disabilities criminal sanctions should be pursued with adequate sentencing and rehabilitation. Supports for an individual with an intellectual disability to participate in

\textsuperscript{1062} Extract from interviews with BIHP3, 6 May 2016 and BIHP5, 7 August 2016, transcripts on file with researcher.
\textsuperscript{1063} All of the NI participants acknowledged the needs of their peers with disabilities but in BiH there was only acknowledgement of the individual’s needs.
\textsuperscript{1064} Extract from interview with NIP1, 22 March 2016, transcript on file with researcher.
\textsuperscript{1065} Lived experience participants in both jurisdictions commented on some negative interactions with the general population.
court proceedings to challenge discrimination or in criminal proceedings – providing statements, receiving information in accessible formats, supports to provide evidence in court – should be made available.

**Recommendation 5**: State investment in self-advocacy initiatives is required to equip persons with intellectual disabilities with knowledge and skills to engage in decision making processes that affect them. Self-advocacy equips individuals to communicate their will and preferences regarding where and with whom they live and how they organise their lives. This would facilitate compliance with Article 19 as well as Article 4(3) of the UNCRPD.

Self-advocacy for adults with intellectual disabilities was not developed on a national scale in either jurisdiction. Two NI participants with intellectual disabilities referenced meeting politicians through their self advocacy work while the BiH participants referred to social meetings and arts and crafts as part of what they described as self advocacy work. The human rights and equality agenda of the peace process in NI was referenced numerous times by both professionals and lived experiences and there were varying degrees of knowledge about the UNCRPD in both jurisdictions. NI participants provided greater examples of engaging in self-advocacy activities – attending events, meeting with politicians and contributing to their communities – than their counterparts in Bosnia for whom living independently was a relatively new concept at this stage in their lives.

**Recommendation 6**: States must collect, analyse and distribute data on the population of persons with intellectual disabilities. This would facilitate compliance with Article 31 UNCRPD as well as informing the planning for initiatives which are Article 19 compliant.

All of the above recommendations must integrate mechanisms for collecting accurate data, disaggregated for age and gender. Article 31 of the UNCRPD relates to the collection and retention of data by states for the purposes of improved implementation of UNCRPD. There is a lack of coordinated data collection within NI and BiH and this impacts on the ability of the states to plan effectively for current and future demands on disability services. Public awareness raising campaigns should be bolstered by informed data from national statistics offices which could also collaborate with civil society organisations to produce reports on attitudes towards minorities, which should include persons with intellectual disabilities. In NI population data would assist in recognition of the need for disability legislation and policies devised at Westminster to be extended to NI should direct rule be enforced in the future with the uncertainty of the British exit from the EU. In BiH the much needed process of
deinstitutionalisation to support independent living will require detailed information to ensure that adequate supports are available within the community. The future membership of the EU for BiH will require the State to ensure that EU Structural Funds are not utilised to continue institutionalisation.\textsuperscript{1066}

5.5 Conclusion
This thesis has outlined the applicable legislative and policy provisions, and provided an insight into the lives of persons with intellectual disabilities, with a focus on the right to live independently in NI and BiH from the pre-conflict years to the post-conflict period.

Chapter 1 introduced the research and the methodology used to conduct this comparative socio-legal research which has used international human rights law as a theoretical framework for examining NI and BiH compliance with Article 19 UNCRPD. It discussed Disability Studies and qualitative research methods for persons with intellectual disabilities. It also outlined how the qualitative research was designed and executed using Clarke and Braun’s method of thematic analysis.\textsuperscript{1067}

Chapter 2 highlighted the violations of fundamental human rights experienced by persons with intellectual disabilities until the mid-20\textsuperscript{th} Century. Activism by persons with physical disabilities to demand supports to live independently and reject a medical, patriarchal attitude towards persons with disabilities was the starting point for progress in the US. The Independent Living Movement was organised by a student body in California and spread throughout the US and to Europe through networking and support from the lead activists. International initiatives such as the 1981 United Nations Year of the Disabled proved the effectiveness of the disability activism in a short period of time. However, it was not until 2006 that the international community recognised the exclusion of persons with disabilities from the rights protections afforded through existing international human rights law and a disability specific Convention was agreed upon. Article 19 was a contentious issue during discussions by States during the drafting process. The role of families and carers as well as clarification on the right to independent living encompassing the right to supports in order to access the community dominated the discussions. Since States have been examined on their UNCRPD compliance the Committee on the Rights of Persons with Disabilities has produced extensive guidance through Concluding Observations, country specific investigations and

\textsuperscript{1066} Extract from interview with BIHP5, 7 August 2016. See also discussion at Section 2.11.6.
\textsuperscript{1067} Discussed at Section 1.7.
General Comment No. 5 on the realisation of Article 19. Issues of continued funding of institutions and lack of appropriate community based living options are reoccurring across States and prevent full compliance with Article 19.

Chapters 3 and 4 considered the events of the ethno-nationalist conflict in each jurisdiction and highlighted the lack of literature on the experiences of same for persons with intellectual disabilities. Both jurisdictions implemented disability services which were medically focused and patriarchal during the pre-conflict years\textsuperscript{1068}. This was the antithesis of the Independent Living Movement occurring in the U.S. at the same time.

Participants in both jurisdictions experienced institutionalisation and living in the community with families before, during and after the conflict, with some participants experiencing a mixture of both at different periods of their lives. During the conflict in BiH disability services were often reduced to distributing basic survival supplies while in NI legislation and policies progressed, albeit at a slower rate than their neighbouring jurisdictions in the rest of the UK. Many policies contained positive rhetoric for the time period but were not referenced by participants in the qualitative research so their impact on the ground is questionable\textsuperscript{1069}.

The effects of the conflict and peace processes in both jurisdictions continue today. The current political landscape in each state is a direct result of the conflicts. The peace processes in both jurisdictions attempted to appease the ethnic populations affected. The post-conflict governance structures impact elements of the lives of all citizens, but particularly persons with intellectual disabilities who are reliant on public services. Disability services are delivered through health and social welfare bodies in each jurisdiction and the consensus from participants in the qualitative research was that disability issues are not a priority for the respective governments. The focus of politicians on legacy issues from the conflicts are often blamed for lack of progress and allocation of resources to implement disability rights.

As referenced in the Methodology section, McDougal’s method for comparative legal analysis was used to design the research to answer the research questions\textsuperscript{1070}. McDougal highlights that common elements across jurisdictions are values, bases of power, limitations of power and the effect of the exertion of power. Chapter 2 outlined how the values and ethos of the independent living movement was enshrined in UNCRPD. These values, particularly

\textsuperscript{1068} Extracts from interviews with NIP2, NIP4, BIHP3 and BIHP5, April, May and August 2016, transcripts on file with researcher.
\textsuperscript{1069} Health and wellbeing
\textsuperscript{1070} Discussed at Section 1.5.1.
Article 19, created a foundation against which to measure the legislation, policies and lived experiences of persons with intellectual disabilities within NI and BiH. The bases of power in each jurisdiction was discussed in Chapters 3 and 4 – legislation from the UK influenced NI during the Troubles and a constantly evolving Constitution from socialism to the post conflict Dayton Accords influenced the legal framework in BiH. The limitations on government to devise legislation and deliver services during the periods of conflict and the role of politics rooted in ethnic tensions was outlined throughout Chapters 3 and 4. The current government administrations in each jurisdiction which are obliged to adhere to UNCRPD demonstrate the exertion of powers and influences with disability being perceived as a low level priority in both states. McDougal’s final element in comparative analysis is the consideration of the impact the exertion of powers have on the target group, persons with intellectual disabilities. The continued institutionalisation and exclusion from full participation in communities demonstrates the negative effect of the lack of implementation of current policies and practices which have the potential to be UNCRPD compliant.

The ratification of UNCRPD has the potential to improve the situation of persons with intellectual disabilities in both jurisdictions but it impact to has been minimal at the grassroots level. There is knowledge of UNCRPD and obligations arising from it among high level government members but this has not translated to the commitment of resources to achieve those obligations. Public awareness of UNCPRD remains low outside of academic and policy sectors in both jurisdictions but civil society organisations have attempted to inform adults with intellectual disabilities of their rights. This has been achieved in a disjointed manner across regions. There is a correlation in NI of activities related to human rights with a republican ethos which is a legacy of the origins of Troubles1071. In BiH there is no association of any ethnicity with a human rights movement and the highly bureaucratic nature of social services across ten cantons has prevented the emergence of a national Independent Living Movement1072. Ultimately there are examples of Article 19 compliance in both jurisdictions, mostly through civil society initiatives, but the conflict and the post conflict situations in each state has deterred progress on the realisation of Article 19 rights for adults with intellectual disabilities in Northern Ireland and Bosnia Herzegovina.

1071 Extracts from interviews with NIP2 and NILE1 and NILE2. March and April 2016, transcripts on file with researcher.
1072 Discussed at Section 4.5.2.
This thesis has not attempted to capture the entirety of the experiences of persons with intellectual disabilities in Northern Ireland and Bosnia Herzegovina. It does however address a significant gap in the literature and points toward a need for further analysis of the experiences of persons with intellectual disabilities during the conflicts in these jurisdictions. The benefits of this research extends to considering the experiences of persons with intellectual disabilities when investing finances and resources in the immediate aftermath of conflict, or similar disasters. Disability and conflict are issues which are well written about in general but intellectual disability has been ignored in the literature pertaining to the conflicts in both Northern Ireland and Bosnia Herzegovina. Along with the contributions of the professional participants in Northern Ireland asserting the novelty of this research topic the dearth in the literature evidences the novel element contribution of this research to the field. In Bosnia Herzegovina the literature described the conditions of war and of institutions for those segregated from society but details on intellectual disability specifically were not available. The military service by men with intellectual disabilities has been a particularly novel finding to which no references had been made in the literature.

The research suggests that the experiences of persons with intellectual disabilities of conflict is unique among the general population. There are similarities in the experiences of the lived experience participants in NI and BiH – exclusion from communities, segregated services, lack of information about the causes of conflict and peace process contemporaneously, relegation of their rights in the post-conflict society which failed to recognise their ethnic identities. In NI the protracted nature of the conflict and the ethos of a human rights campaign initiating the Troubles led to a more considered peace process which was based on a framework of rights and equality. This has yet to be fully realised for persons with intellectual disabilities. It is preferable however to the shorter more extreme conflict which erupted in BiH which was based on aggression and dominance between multiple ethnicities over territories. The Dayton Peace Accords then focused on division of territories and placating ethnic leaders and human rights were not to the fore of discussion. Accordingly the post-conflict society was fragmented and human rights continue to be neglected with the rights of persons with intellectual disabilities afforded low levels of priority. The combined analysis of literature and qualitative research has demonstrated the disconnect between the rhetoric of states regarding disability laws and policies, and the impact on the ground. The recommendations offer states options through which realisation of Article 19 UNCRPD can
be achieved if undertaken in consultation with persons with intellectual disabilities and in a manner which respects equality and dignity.
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Appendices

Appendix 1 – NVIVO Codebook

Appendix 1073- Codebook\Phase 2 - Generating Initial Codes (Open Coding)

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\(^{1073}\) Codebook - Phase 2 – Generating Initial Coding involved deconstructing the data from its original chronology into an initial set of non-hierarchical codes
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<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Living Arrangement</td>
<td>References to living arrangements</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>References to accommodation and living arrangements, short stay or permanent</td>
<td>10</td>
<td>49</td>
</tr>
<tr>
<td>National Human Rights Institutions</td>
<td>References to NHRI’s in the implementation and monitoring and advocacy of disability rights.</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>National Human Rights Institutions (2)</td>
<td>References to NHRI’s in the implementation and monitoring and advocacy of disability rights.</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Non government organisation</td>
<td>References to the role of NGO’s in the provision of disability services, advocacy and policy.</td>
<td>11</td>
<td>36</td>
</tr>
<tr>
<td>Participation in conflict</td>
<td>References to persons with intellectual disabilities participating, or not, in armed forces and the extent/justifications offered for that.</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Peace process</td>
<td>References to peace efforts, agreements and surrounding events and how people experienced it</td>
<td>14</td>
<td>22</td>
</tr>
<tr>
<td>Policies</td>
<td>References to specific policy documents or reports</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Positive initiatives</td>
<td>Steps taken by individuals, organisations,</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Phase 2 – 38 Initial Codes Developed</td>
<td>Code Definitions for Coding Consistency (Rules for Inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
</tr>
<tr>
<td>-------------------------------------</td>
<td>---------------------------------------------------------------</td>
<td>------------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Religion and ethnicity</td>
<td>Supports or government that positively affected the rights of persons with intellectual disabilities</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Religious charities</td>
<td>References to involvement of religious organisations and differences of treatment based on ethnicity</td>
<td>19</td>
<td>33</td>
</tr>
<tr>
<td>Services accessed within community</td>
<td>Reference to participation in communities, amenities, social affairs etc.</td>
<td>13</td>
<td>32</td>
</tr>
<tr>
<td>Transport</td>
<td>References to transport services</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>References to UNCRPD standards, ethos, rules and incorporation domestically.</td>
<td>9</td>
<td>12</td>
</tr>
</tbody>
</table>
### Phase 3 – 38 Initial CodesCollapsed to 8 Categories of codes

<table>
<thead>
<tr>
<th>Code Definitions for Coding Consistency (Rules for Inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Disability services References to existence of, descriptions of delivery and standards of services in BiH</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>Independent living programmes References to independent living in the past, present or future for participants</td>
<td>12</td>
<td>38</td>
</tr>
<tr>
<td>Historic References to provision of services historically</td>
<td>16</td>
<td>35</td>
</tr>
<tr>
<td>Law and policy References to laws and policies relating to persons with disabilities</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>International laws References to international laws, obligations and UN Conventions</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>How law and policy is made description of the process of making disability related laws and policies</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Policies References to specific policy documents or reports</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Human Rights References to a culture of rights, acknowledgement and recognition of persons with intellectual disabilities as rights holders</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Litigation References to cases and appeals about laws affecting persons with disabilities</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Non government organisation References to the role of NGO’s in the provision of disability services, advocacy and policy.</td>
<td>11</td>
<td>36</td>
</tr>
</tbody>
</table>

1074 Codebook – Phase 3 – Searching for Themes – involved merging, renaming, distilling and clustering related coded into broader categories of codes to reconstruct the data into a framework that makes sense to further the particular piece of analysis.
<p>| Category                        | Description                                                                 | References to NHRI’s in the implementation and monitoring and advocacy of disability rights. | References to provision of services by religious charitable groups | References to economy, political situation, investment received by the state by way of rationalising or explaining the delivery of disability services | References to the conflict - facts, personal experience, changes to society since conflict | References to involvement of religious organisations and differences of treatment based on ethnicity | Impact of the conflict on disability services. | References to peace efforts, agreements and surrounding events and how people experienced it | References to persons with intellectual disabilities participating, or not, in armed forces and the extent/justifications offered for that. | References to individuals and or organisations involved in lobbying for law, policy and services | References to daily life and activities- family, friends, employment | References to accommodation and living arrangements, short stay or permanent |</p>
<table>
<thead>
<tr>
<th>Category</th>
<th>Description</th>
<th>Count 1</th>
<th>Count 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family support</td>
<td>References to involvement of family and informal care to provide supports to persons with disabilities</td>
<td>17</td>
<td>38</td>
</tr>
<tr>
<td>Experience of conflict</td>
<td>References to participants lived experiences and knowledge of conflict</td>
<td>9</td>
<td>33</td>
</tr>
<tr>
<td>Services accessed within community</td>
<td>Reference to participation in communities, amenities, social affairs etc.</td>
<td>13</td>
<td>32</td>
</tr>
<tr>
<td>Employment</td>
<td>References to employment</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td>Activities provided by service</td>
<td>References to engaging in activities and events organised by disability services</td>
<td>9</td>
<td>18</td>
</tr>
<tr>
<td>Comments on the research</td>
<td>Reference by participants for the need or novelty of the research project</td>
<td>2</td>
<td>2</td>
</tr>
</tbody>
</table>
### Appendix 1075 - Codebook: Phase 4 - Reviewing Themes (Drilling Down)

<table>
<thead>
<tr>
<th>Comments on the research</th>
<th>Code Definitions for Coding Consistency (Rules for Inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Conflict</td>
<td>Reference by participants for the need or novelty of the research project</td>
<td>2</td>
<td>2</td>
</tr>
<tr>
<td>Disability service impact</td>
<td>Impact of the conflict on disability services.</td>
<td>11</td>
<td>26</td>
</tr>
<tr>
<td>Participation in conflict</td>
<td>References to persons with intellectual disabilities participating, or not, in armed forces and the extent/justifications offered for that.</td>
<td>11</td>
<td>13</td>
</tr>
<tr>
<td>Disability experience</td>
<td>What has been the participant’s involvement with disability services and policy?</td>
<td>12</td>
<td>36</td>
</tr>
<tr>
<td>Peace process</td>
<td>References to peace efforts, agreements and surrounding events and how people experienced it</td>
<td>14</td>
<td>22</td>
</tr>
<tr>
<td>Religion and ethnicity</td>
<td>References to involvement of religious organisations and differences of treatment based on ethnicity</td>
<td>19</td>
<td>33</td>
</tr>
<tr>
<td>Development of country</td>
<td>References to economy, political situation, investment received by the state by way of rationalising or explaining the delivery of disability services</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td>Disability representation</td>
<td>References to individuals and or organisations involved in lobbying for law, policy and services</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>Disability services</td>
<td>References to existence of, descriptions of delivery and standards of services in BiH</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>Historic</td>
<td>References to provision of services historically</td>
<td>16</td>
<td>35</td>
</tr>
</tbody>
</table>

---

1075 Codebook – Phase 4 – Reviewing Themes involved breaking down the now reorganised codes in to sub-codes to better understand the meanings embedded therein.
<table>
<thead>
<tr>
<th>Phase 3 – 14 New Sub-Categories Developed</th>
<th>Code Definitions for Coding Consistency (Rules for Inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Education</td>
<td>References to school and education</td>
<td>12</td>
<td>20</td>
</tr>
<tr>
<td>Independent living programmes</td>
<td>References to independent living in the past, present or future for participants</td>
<td>12</td>
<td>38</td>
</tr>
<tr>
<td>Advocacy</td>
<td>References to advocacy organisations or individuals and the mechanisms available within the state to facilitate or hamper that.</td>
<td>12</td>
<td>15</td>
</tr>
<tr>
<td>Failing policies</td>
<td>Any laws or policies that failed to protect there rights of persons with intellectual disabilities and facilitate independent living</td>
<td>5</td>
<td>13</td>
</tr>
<tr>
<td>Positive initiatives</td>
<td>Steps taken by individuals, organisations, supports or government that positively affected the rights of persons with intellectual disabilities.</td>
<td>7</td>
<td>13</td>
</tr>
<tr>
<td>Law and policy</td>
<td>References to laws and policies relating to persons with disabilities</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>How law and policy is made</td>
<td>Description of the process of making disability related laws and policies</td>
<td>9</td>
<td>23</td>
</tr>
<tr>
<td>Human Rights</td>
<td>References to a culture of rights, acknowledgement and recognition of persons with intellectual disabilities as rights holders</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>International laws</td>
<td>References to international laws, obligations and UN Conventions</td>
<td>6</td>
<td>26</td>
</tr>
<tr>
<td>UNCRPD</td>
<td>References to UNCRPD standards, ethos, rules and incorporation domestically.</td>
<td>9</td>
<td>12</td>
</tr>
<tr>
<td>Government</td>
<td>Government set up, support to civil society, bureaucracy, disability, social issues and rights as a priority</td>
<td>11</td>
<td>53</td>
</tr>
<tr>
<td>Corruption</td>
<td>References to unethical or corrupt practices by members of government -local or national - that negatively impact on the services and rights of persons with intellectual disabilities as perceived by the researcher</td>
<td>5</td>
<td>9</td>
</tr>
<tr>
<td>Phase 3 – 14 New Sub-Categories Developed</td>
<td>Code Definitions for Coding Consistency (Rules for Inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-------------------------------------------------------------</td>
<td>----------------</td>
<td>------------------------</td>
</tr>
<tr>
<td>Idea (2)</td>
<td>References to initiatives by governments</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>Working bodies, sub groups</td>
<td>References to cases and appeals about laws affecting persons with disabilities</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Litigation</td>
<td>References to cases and appeals about laws affecting persons with disabilities</td>
<td>7</td>
<td>14</td>
</tr>
<tr>
<td>Policies</td>
<td>References to specific policy documents or reports</td>
<td>4</td>
<td>20</td>
</tr>
<tr>
<td>Life experiences</td>
<td>References to daily life and activities- family, friends, employment</td>
<td>12</td>
<td>18</td>
</tr>
<tr>
<td>Activities provided by service</td>
<td>References to engaging in activities and events organised by disability services</td>
<td>9</td>
<td>18</td>
</tr>
<tr>
<td>Employment</td>
<td>References to employment</td>
<td>8</td>
<td>21</td>
</tr>
<tr>
<td>Experience of conflict</td>
<td>References to participants lived experiences and knowledge of conflict</td>
<td>9</td>
<td>33</td>
</tr>
<tr>
<td>Family support (3)</td>
<td>References to involvement of family and informal care to provide supports to persons with disabilities</td>
<td>17</td>
<td>38</td>
</tr>
<tr>
<td>Living Arrangements</td>
<td>References to accommodation and living arrangements, short stay or permanent</td>
<td>10</td>
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<tr>
<td>Living Arrangement</td>
<td>References to living arrangements</td>
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<td>4</td>
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<tr>
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<td>Services accessed within community</td>
<td>Reference to participation in communities, amenities, social affairs etc.</td>
<td>13</td>
<td>32</td>
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<tr>
<td>Transport</td>
<td>References to transport services</td>
<td>8</td>
<td>14</td>
</tr>
<tr>
<td>Non government organisation</td>
<td>References to the role of NGO’s in the provision of disability services, advocacy and policy.</td>
<td>11</td>
<td>36</td>
</tr>
<tr>
<td>Phase 3 – 14 New Sub-Categories Developed</td>
<td>Code Definitions for Coding Consistency (Rules for Inclusion)</td>
<td>Interviews Coded</td>
<td>Units of Meaning Coded</td>
</tr>
<tr>
<td>-----------------------------------------</td>
<td>-------------------------------------------------------------</td>
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</tr>
<tr>
<td>National Human Rights Institutions</td>
<td>References to NHRI’s in the implementation and monitoring and advocacy of disability rights.</td>
<td>9</td>
<td>17</td>
</tr>
<tr>
<td>Religious charities</td>
<td>References to provision of services by religious charitable groups</td>
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</table>
## Appendix 1076 - Codebook\Phase 5 - Defining & Naming Themes (Data Reduction)

<table>
<thead>
<tr>
<th>Phase 5 – 8 Categories Conceptually Mapped to 5 Themes - Named &amp; Defined</th>
<th>Code Definitions for Coding Consistency (Rules for Inclusion)</th>
<th>Interviews Coded</th>
<th>Units of Meaning Coded</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services during pre-conflict</td>
<td>References to existence of, descriptions of delivery and standards of services in BiH</td>
<td>15</td>
<td>78</td>
</tr>
<tr>
<td>Disability services</td>
<td>References to individuals and or organisations involved in lobbying for law, policy and services</td>
<td>14</td>
<td>54</td>
</tr>
<tr>
<td>Disability representation</td>
<td>References to existence of, descriptions of delivery and standards of services in BiH</td>
<td>10</td>
<td>24</td>
</tr>
<tr>
<td>UNCRPD ratification impact</td>
<td>References to laws and policies relating to persons with disabilities</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>Law and policy</td>
<td>References to laws and policies relating to persons with disabilities</td>
<td>11</td>
<td>44</td>
</tr>
<tr>
<td>Impact of peace process on disability rights</td>
<td>References to economy, political situation, investment received by the state by way of rationalising or explaining the delivery of disability services</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td>Development of country</td>
<td>References to economy, political situation, investment received by the state by way of rationalising or explaining the delivery of disability services</td>
<td>12</td>
<td>28</td>
</tr>
<tr>
<td>Services during period of conflict</td>
<td>References to the conflict - facts, personal experience, changes to society since conflict</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Conflict</td>
<td>References to the conflict - facts, personal experience, changes to society since conflict</td>
<td>10</td>
<td>25</td>
</tr>
<tr>
<td>Childhood living arrangements</td>
<td>References to daily life and activities- family, friends, employment</td>
<td>12</td>
<td>18</td>
</tr>
<tr>
<td>Life experiences</td>
<td>References to daily life and activities- family, friends, employment</td>
<td>12</td>
<td>18</td>
</tr>
</tbody>
</table>

1076 Codebook – Phase 5 – Defining and Naming Themes involved conceptually mapping and collapsing categories into a broader thematic framework.
Appendix 5 – Example of Annotations to Preserve Context

Annotations integrated soft data such as field notes and observations, coding assumptions, missing contexts lost in the transcribing process and researcher’s thoughts and ideas into the primary data to support analysis and deeper understanding of participants’ world view.
Appendix 6 – Example of Analytical Memos to Facilitate a Systematic Review of the Thematic Framework

Analytical memos facilitated a systematic review of the thematic framework as a means of drafting initial findings and using writing as the tool to prompt deeper thinking and questioning of the data.
Ms Aine Sperrin
Centre for Disability Law
and Policy NUI Galway

Dear Ms Sperrin

**Ethics Application:** A comparative analysis of the implementation of Article 19 of the United Nations Convention on the Rights of Persons with Disability in states which have recently experienced conflict

I write to you regarding the above proposal which was submitted for ethical review. Having reviewed your response to my letter, I am pleased to inform you that your proposal has been granted **APPROVAL.**

All NUI Galway Research Ethic Committee approval is given subject to the Principal Investigator submitting annual and final statements of compliance. The first statement is due on or before 31st December 2016.
Please see section 7 of the REC’s Standard Operating Procedures for further details which also includes other instances where you are required to report to the REC.

Yours sincerely

Allyn Fives

Research Ethics Committee
Appendix 3 – Consent form template

PARTICIPANT INFORMATION AND CONSENT FORM

STUDY TITLE: A comparative analysis of the implementation of Article 19 of the United Nations Convention on the Rights of Persons with Disability in states which have recently experienced conflict.

NAME OF PRINCIPAL INVESTIGATORS: Aine Sperrin, BCL, LLM, Irish Research Council Scholar and PhD Candidate, Centre of Disability Law and Policy, NUI Galway, Galway, Ireland

You are being invited to participate in a research study. Thank you for taking time to read this.

WHAT IS THE PURPOSE OF THIS STUDY?

The aim of the research is to extract policies, legislation and practices which have been utilised in the post conflict states of Northern Ireland and Bosnia and Herzegovina to deliver human rights compliant services to adults with intellectual disabilities, with a particular emphasis on independent living and community participation. Independent living is provided for under Article 19 of the United Nations Convention on the Rights of Persons with Disabilities. The experiences of these post conflict states can provide guidance for states that have not yet ratified the Convention as well as states that will emerge from conflict in the future. The key research questions are:

1. How effectively have the states implemented Article 19 of UNCRPD to impact positively on the lives of persons with intellectual disabilities?
2. What impact did the conflicts and peace processes have on the rights and lives of persons with disabilities?
3. What are the perceived pre-conditions necessary for implementing independent living programmes through disability services?
WHY HAVE I BEEN CHOSEN?

You have been identified as potentially being in a position to offer a unique insight into the practicalities of delivering disability services in a post-conflict state which is obliged to be compliant with the United Nations Convention on the Rights of Persons with Disabilities.

WHAT WILL HAPPEN IF I VOLUNTEER?

I will contact you to arrange a time, date and place for interview at a location of most convenience to you. The interview will be very informal and the topics discussed will range from how disability services have changed from the beginning of a time of conflict to the present day. The questions will allow you to give your own experiences of laws, policies and human rights enforcement mechanisms for persons with intellectual disabilities.

ARE THERE ANY BENEFITS FROM MY PARTICIPATION?

The information gained from the interviews will be extremely important in identifying the strengths and weaknesses of governments and their departments in fulfilling their obligations under the UNCRPD. Potential for improving the experiences of persons with intellectual disabilities in participating in their communities and living independently will also be identified. It is hoped that the results of this research will be published and communicated to policy makers in Ireland with the potential for further reaching communications.

ARE THERE ANY RISKS INVOLVED IN PARTICIPATING?

The topics being discussed will revolve around the provision of disability services from the 1980’s onward. It is acknowledged that some experiences of disability services are negative. The interview will not focus on negative incidents of disability services or incidents of conflict or violence but there are risks of some discomfort when recounting experiences from these time periods.

WHAT HAPPENS IF I DO NOT AGREE TO PARTICIPATE?
Your participation is entirely voluntary.

If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect your rights in any way.

CONFIDENTIALITY

Your identity will remain confidential. You will select a pseudonym. Your name will not be published or disclosed to anyone.

WHO IS ORGANISING AND FUNDING THIS RESEARCH?

Aine Sperrin, a 3rd year PhD student at the Centre of Disability Law and Policy, supported by her research supervisor, Dr. Eilionóir Flynn and funded by the Irish Research Council.

WILL I BE PAID FOR TAKING PART IN THIS STUDY?

No.

WILL MY EXPENSES BE COVERED FOR TAKING PART IN THIS STUDY?

No. Where possible interviews will be held at your convenience with no cost to yourself.

HAS THIS STUDY BEEN REVIEWED BY AN ETHICS COMMITTEE?

Under review currently

CONTACT DETAILS

If you would like any further information about the study, without any obligation to take part, please contact:

Aine Sperrin, PhD Student, Centre of Disability Law and Policy, NUI Galway, Galway, Ireland. a.sperrin1@nuigalway.ie
1. I confirm that I have received a copy of the Information Sheet for the above study. I have read it and I understand it. I have received an explanation of the nature, purpose, duration and foreseeable effects and risks of the study and what my involvement will be.

2. I have had time to consider whether to take part in this study and I have had the opportunity to ask questions.

3. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.

4. By signing this consent form, I agree to take part in the above study.

_____________________________ Participant Name

Participant Address: ____________________________________________

_________________________________________________________

Contact no: _______________________

**Please return this consent form to:**

Aine Sperrin, PhD Student, Centre of Disability Law and Policy, NUI Galway, Galway, Ireland.

a.sperrin1@nuigalway.ie
| I want to learn about life for people with disabilities in Northern Ireland/ Bosnia and Herzegovina |
| I want people with intellectual disability to be included in their community |
| You can help by telling your story. This will take between 40 minutes and 1 hour |
| I want to know how you participate in your community |
| I want to know how your life has changed. |
I want to know if the Peace Process has made your life better

What Will I Do With Your Information?

<table>
<thead>
<tr>
<th>Examples of what worked well: I hope to show how people with disabilities can be a part of the community when governments work for peace</th>
</tr>
</thead>
<tbody>
<tr>
<td>happy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Examples of what didn’t work: I want to make sure that people with disabilities are not excluded in the future.</th>
</tr>
</thead>
<tbody>
<tr>
<td>unhappy</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Taking part is voluntary</th>
</tr>
</thead>
<tbody>
<tr>
<td>Your information will be confidential</td>
</tr>
<tr>
<td>My name is........................................</td>
</tr>
<tr>
<td>------------------------------------------</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Please tick</th>
</tr>
</thead>
<tbody>
<tr>
<td>I have enough information about the research.</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>I was able to ask questions about the research.</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>I understand that what I say will be recorded.</td>
</tr>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>Anne</td>
</tr>
<tr>
<td>------</td>
</tr>
<tr>
<td>Mary</td>
</tr>
<tr>
<td></td>
</tr>
<tr>
<td></td>
</tr>
</tbody>
</table>
I understand that taking part means having a chat, but nothing more.

| ☺ Yes | ☹ No |

I agree to take part in the research.

| ☻ Yes | ☹ No |

Date ..................................................

Sign ..................................................
Appendix 4 - Supporting materials

English Easy to Read supporting materials.

<table>
<thead>
<tr>
<th>about you</th>
<th>Where have you lived?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>address</th>
<th>What services did you use?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>day service</th>
<th>Did you go to school?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>bus</strong></td>
<td>How did you get there?</td>
</tr>
<tr>
<td>---------</td>
<td>-----------------------</td>
</tr>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><img src="image" alt="Sunrise" /></th>
<th>What did you do during the day?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**About the conflict**

<table>
<thead>
<tr>
<th><img src="image" alt="Map of Yugoslavia" /></th>
<th>Do you know about the war? Can you tell me your experience?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th><img src="image" alt="Fist" /></th>
<th>Did your services ever stop?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

330
<table>
<thead>
<tr>
<th>Who did you talk to about the conflict?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you know about the Peace Process?</td>
</tr>
<tr>
<td>Did you vote in the Good Friday Agreement referendum?</td>
</tr>
<tr>
<td>Who did you talk to about the new Government?</td>
</tr>
<tr>
<td>Question</td>
</tr>
<tr>
<td>------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Do you live independently?</td>
</tr>
<tr>
<td>Did your service tell you about living in the community?</td>
</tr>
<tr>
<td>Did you have help to move?</td>
</tr>
<tr>
<td>What activities do you like?</td>
</tr>
<tr>
<td>Do you have a job?</td>
</tr>
<tr>
<td>What supports do you use?</td>
</tr>
<tr>
<td>--------------------------</td>
</tr>
<tr>
<td>How do you pay for supports?</td>
</tr>
<tr>
<td>Are you part of an advocacy group?</td>
</tr>
<tr>
<td>What work does your group do?</td>
</tr>
<tr>
<td>Does your group get funding and support?</td>
</tr>
</tbody>
</table>

**About the Community**
<table>
<thead>
<tr>
<th>Do you go into the local community?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you use public transport?</td>
</tr>
<tr>
<td>What services do you use in the local community?</td>
</tr>
<tr>
<td>What is good about community services?</td>
</tr>
<tr>
<td>What is bad about community services?</td>
</tr>
</tbody>
</table>
### O tebi

<table>
<thead>
<tr>
<th>About you</th>
<th>Gde si živela?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Address</td>
<td>Koje usluge ste koristili?</td>
</tr>
<tr>
<td>Day Service</td>
<td>Da li ste išli u školu?</td>
</tr>
<tr>
<td>Bus</td>
<td>Kako ste stigli tamo?</td>
</tr>
<tr>
<td>Šta ste radili tokom dana?</td>
<td>About the conflict</td>
</tr>
<tr>
<td>--------------------------</td>
<td>--------------------</td>
</tr>
<tr>
<td>Da li znate za rat? Možete li mi reći vaše iskustvo?</td>
<td>Da li su vaše usluge ikada zaustavljale?</td>
</tr>
<tr>
<td>Kome ste razgovarali o sukobu?</td>
<td></td>
</tr>
<tr>
<td>Da li znate za Dejtonski mirovni sporazum?</td>
<td></td>
</tr>
<tr>
<td>------------------------------------------</td>
<td></td>
</tr>
<tr>
<td>Sa kim si razgovarao o novoj Vladi?</td>
<td></td>
</tr>
<tr>
<td>o samostalnom životu</td>
<td></td>
</tr>
<tr>
<td>Da li živite samostalno?</td>
<td></td>
</tr>
<tr>
<td>Da li vam je služba rekla da živite u zajednici?</td>
<td></td>
</tr>
<tr>
<td>Da li vam je služba rekla da živite u zajednici?</td>
<td></td>
</tr>
<tr>
<td><strong>help</strong></td>
<td>Da li ste imali pomoć da se pomerite?</td>
</tr>
<tr>
<td><strong>activities</strong></td>
<td>Koje aktivnosti volite?</td>
</tr>
<tr>
<td><strong>job</strong></td>
<td>Imate li posao?</td>
</tr>
<tr>
<td><strong>Koja podrška koristite?</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Kako plaćate podršku?</strong></td>
<td></td>
</tr>
<tr>
<td>Image</td>
<td>Question</td>
</tr>
<tr>
<td>-------</td>
<td>----------</td>
</tr>
<tr>
<td><img src="family_friends_and_advocate.png" alt="Image" /></td>
<td>Da li ste deo grupe za zastupanje?</td>
</tr>
<tr>
<td><img src="office.png" alt="Image" /></td>
<td>Koji posao radi vaša grupa?</td>
</tr>
<tr>
<td><img src="money.png" alt="Image" /></td>
<td>Da li vaša grupa dobija finansije i podršku?</td>
</tr>
<tr>
<td><img src="community.png" alt="Image" /></td>
<td>o zajednici</td>
</tr>
<tr>
<td><img src="house.png" alt="Image" /></td>
<td>Da li ideš u lokalnu zajednicu?</td>
</tr>
<tr>
<td><img src="bus.png" alt="Image" /></td>
<td>Da li koristite javni prevoz?</td>
</tr>
<tr>
<td><strong>community</strong></td>
<td>Koje usluge koristite u lokalnoj zajednici?</td>
</tr>
<tr>
<td>---------------</td>
<td>--------------------------------------------</td>
</tr>
<tr>
<td><strong>good staff</strong></td>
<td>Šta je dobro za usluge u zajednici?</td>
</tr>
<tr>
<td><strong>bad</strong></td>
<td>Šta je loše za usluge u zajednici?</td>
</tr>
</tbody>
</table>
Appendix 5 – List of Questions

List of Questions for Professional Group

What has been your experience with disability services? Have you worked in any other jurisdictions?

How does your role influence disability policy?

Does your organisation get the necessary government support to carry out your role? What could be improved?

How are disability laws and policies made in your jurisdiction? Is there participation and inclusion of persons with intellectual disabilities as stakeholders?

How are these laws and policies enforced? Is it adequate? How can it be improved?

Does the National Human Rights Institution in BiH have an officer/staff dedicated to monitoring Convention on Rights of Persons with Disabilities?

Is there a duty for public services to consider human rights in their work? Has this been fulfilled?

How aware are staff in government departments and on the ground of human rights and equality issues?

What, if any, progress has been made in improving services for persons with intellectual disabilities during your career?

What influence did the conflict and peace processes have on these developments?

Has ratification of the UNCRPD brought about any changes in the disability law and policy sphere?

Are there consultation mechanisms for representative organisations? How/Have these groups involvement resulted in change?

Are there key reports, policies or litigation which have positively influenced service provision?

Have these been effectively implemented/ actual benefits to stakeholders?

How influential have charitable/religious based service providers been in wider social policy?
How is disability perceived by the general public?

Are there any future initiatives that you are aware of?

What should these initiatives contain or include?

List of Questions for Service-users/self advocates group

Where did you live before the conflict started?

Did you avail of disability services?

Can you describe these services, daily routine?

Did you get a chance to go to school?

Did services or your support network continue during the conflict? Yes/No

After the conflict how were your services and supports different?

Were you familiar with the peace process and the politics after the conflict?

Have you heard about the UNCRPD?

Does your service talk about the UNCRPD or laws that apply to persons with intellectual disabilities?

Do you live independently now?

How were you prepared for this (if moved from institutional/residential services?)

What supports do you have to participate in the community?

What are the best and worst accessible services in your community?

Are you involved with an advocacy group? Does the group get good support – funding, staff, does the public know about the group?

What work does the group do?

What do you think should be done to improve the lives of persons with intellectual disabilities in your country?
Appendix 6 – Template of Confidentiality agreements

TRANSLATOR CONFIDENTIALITY AGREEMENT

I, ______________________, agree to interpret for the qualitative interviews conducted in Bosnia and Herzegovina by Aine Sperrin – PhD Candidate at the Centre of Disability Law and Policy at NUI Galway, Ireland.

I hereby agree not to reveal the content of these discussions/ documents to anyone outside this process. I also agree to interpret accurately and faithfully, even if the statements made or queries raised are contrary to my own beliefs.

Signed (interpreter):

Address: