



**DRAFT Shadow Report on the Implementation  
of the Convention on the Rights of Persons with  
Disabilities in Northern Ireland**

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### **List of Abbreviations**

ASMR	Age Standard Morality Rate
BDA	British Deaf Association
CDSA	Children with Disabilities Strategic Alliance in Northern Ireland
DoH	Department of Health (NI)
DfC	Department for Communities (NI)
DDA	Disability Discrimination Act (DDA) 1995
DLA	Disability Living Allowance
DPO	Disabled People's Organisation
DWP	Department of Work and Pensions
ECNI	Equality Commission for Northern Ireland
HSCT	Health and Social Care Trust
ILF	Independent Living Fund
LLTI	Limiting Long Term Illness
IMNI	Independent Mechanism for Northern Ireland
MS	Multiple Sclerosis
NI	Northern Ireland
NIHRC	Northern Ireland Human Rights Committee
ODI	Office of Disability Issues
OFMDFM	Office of First Minister and Deputy First Minister in Northern Ireland
PIP	Personal Independence Payment
PfG	Programme for Government
PPR	Participation and the Practice of Rights
PSNI	Police Service of Northern Ireland
RNIB	Royal National Institute of Blind People
RNID	Royal National Institute for Deaf People now known as Action on Hearing Loss
RQIA	Regulation and Quality Improvement Authority
SEN	Special Educational Needs
SEND0	Special Educational Needs and Disability (Northern Ireland) Order 2005.

## **Summary of Key Issues**

Following a roundtable event with DPO's, Civil Society

Organisations and disabled people in February the key priorities were identified.

### **1) Implementation of the UNCRPD in Northern Ireland**

The rights based approach by the State in NI is severely lacking.

There is no framework for the implementation of the Convention at a State level in NI and a lack of any strategic direction.

### **2) Participation and Engagement**

The State has to improve the participation and engagement of disabled people at all levels if there is to be any chance of a rights based approach being implemented in NI. Disabled people need to be have power and control over all areas of our lives. Particular attention needs to be given to children with disabilities.

### **3) Retrogression of existing rights**

There are a number of areas where we have concern about the retrogression of rights these include:

- Impact of Welfare Reform (page 35)
- Reduction on social care funding (page 21)
- Closure of ILF to existing users (page 21)
- Impact of Brexit (page 48)

The State has provided no evidence of how it will ensure that there is no retrogression of the rights of disabled people. The NI Executive has not made any response to the CRPD Committee recommendations in the recent Inquiry report.

### **4) Dignity, Choice and Control**

The areas raised in Articles 12,14,15, 19, 23, 25 and 26 are of particular concern (particularly in health and social care but also more widely). The key areas are:

- Implementation of the Mental Capacity Act (NI) (page 15)
- The application of capacity legislation for children and young people (page 16)
- Deprivation of Liberty (page 18)

- Inhuman and degrading treatment (page 19)
- Use of restraint and seclusion (page 19)
- Abuse in residential and community settings (page 19)
- Resettlement from long-stay hospitals and assessment and treatment units (page 23)
- Home and family life (page 28)
- Health inequalities and mortality rates (page 32)
- Lack of Habilitation for children and young people (page 33)

## 5) Accessibility

Articles 9, 22, 24, 28, 29 all raise particular issues in relation to accessibility. The main areas of concern are:

- Transport (page XX)
- Education (page XX)
- Information (page XX)
- Digital services (page XX)
- Rural areas (page XX)
- Privacy in health and social care communication (page XX)
- Housing (page XX)
- Public Office and Electoral Processes (page XX)

## 6) Other Cross-cutting issues

There were also a number of other themes that came through in the engagement and disabled people felt strongly about. These included:

- Awareness Raising (Article 8) (page XX)
- Statistics and Data Collection (Article 31) (page XX)
- Freedom of expression, opinion and access to information (Article 21) (page XX)
- Education (Article 24) (page XX)
- Work and Employment (Article 27) (page XX)

We wish to thank the Committee for this opportunity to submit to it the NI alternative report as part of UK list of issues. We look forward to the opportunity to verbally brief the Committee as a means of amplifying the concerns we have raised within this document.

## 1.1 About Us

Disability Action is a NI pan-disability organisation, we have worked with disabled people, DPO's, Civil Society Organisation across NI in the development of this report.

## 1.2 The Process

We wanted to ensure that this report was about what people with disabilities have told us, the issues that they raise with us everyday and those that are having the biggest impact on people with disabilities attaining their rights in NI.

In March 2014 we held a conference in Belfast for people with disabilities and their organisations. This was attended by around 100 people and the sessions were developed so that each individual was able to tell us what they thought was important to include in the report.

In March 2014 we also issued a general questionnaire and asked people to tell us what they thought were the key areas that needed to be put into this report. The feedback from the conference and the questionnaire have help informed the content of this report.

Organisations were also able to submit evidence to be included in this report and this has been included where possible.

Desktop research was carried out into relevant programmes and policies in NI and reference made to previous research.

Due to the delay in the examination of the UK state report we undertook further engagement during 2015. This engagement activity focussed on younger people and hard to reach groups.

## 1.3 The Scope of the Report

This report only relates to Northern Ireland.

## 1.4 The State in the NI Context

Following the Belfast / Good Friday agreement in 1998, the UK government devolved additional powers to legislative powers to the Assembly. This process of devolution has continued with

powers in relation to policing and justice matters being devolved in 2010.

The NI Assembly has power over devolved or transferred matters which include [agriculture, education, housing, employment, health & social care, social security and policing and justice matters](#).

Equal opportunities and discrimination are 'transferred matters'

under the NI Act 1998 unlike the Scottish Parliament or the National Assembly for Wales.

## 1.5 NI Disability Legislation & Policy

NI has differing legislation and policy in relation to disability. Some of the areas of concern will be raised through the document.

The latest draft Programme for Government (PfG) has a specific indicator on improving the quality of life for people with disabilities.

The Department for Communities (who now have responsibility for disability policy) has engaged widely on what should be in the action plan for this indicator. However, the draft Action plan is yet to receive Executive approval (and there are now fresh elections being held on 2 March 2017). Therefore at the time of writing there is no action plan in place.

## 2.0 **Comments on the Convention Articles**

### 2.1 Articles 1 - 4



**“UNCRPD needs a stronger legal standing to have an impact”**

**“What is the point in a policy if it does not filter down to grass roots level and to the people responsible for implementing it?”**

Disabled people in NI have told us that their main concern is in relation to Article 4 (3) as they do not believe that the State in NI has ensured the involvement of disabled people in policies and programmes which affect us.

There has been no framework for involving disabled people in the monitoring and implementation of the Convention despite a commitment made by the State.

The Northern Ireland ‘Disability Strategy 2012-15’ contained a range of strategic priorities, however, these were not linked to the implementation of the UNCRPD in NI. While action was promised it has been lacking, with no evidence of a strategic action plan to implement UNCRPD.

The latest draft Programme for Government (PfG) from the NI Executive has a specific indicator in relation to disability. The new outcomes based approach being used by government states that they wish to monitor the quality of life for people with disabilities and put in place relevant actions to meet this aim. However, the Action Plan associated with it makes no mention of the implementation of the UNCRPD and is void of any mention of human rights.

The draft PfG has not yet been signed off by the Executive and as new Assembly Elections have now been called for March 2017 it is not known if the draft PfG will continue in its current form.

Disability Strategy was extended to March 2017, and the PfG action plan intended to help move towards a new strategy, the political situation in NI now leaves a vacuum of any strategic plan on the implementation of UNCRPD.

### **Suggested Question**

**What action will the State take to ensure the implementation of the UNCRPD in NI and how will it ensure that appropriate legislation, policies and programmes are in place and resourced?**

## **2.2 Article 5: Equality and non-discrimination**



**“Should all disabled people in the UK be treated differently?”**

**“When is Northern Ireland going to have our laws brought into line with Great Britain?”**

The UK state report comments that the Equality Act 2010 (which applies only to Great Britain) has brought new clarity and coherence to anti-discrimination legislation.

There have been repeated concerns raised that protection for people with disabilities against discrimination in NI has fallen behind GB with less protection against disability discrimination than their counterparts in the rest of the UK and a recent review highlighted seven areas of divergence between the GB and NI in light of the GB Equality Act and UN Committee jurisprudence.

These were in the differences in the definition of disability; in the protection perceived and associative discrimination, indirect discrimination, discrimination arising out of disability and in intersectional discrimination and access to remedies.

As part of the consultation of the draft Programme for Government, The NI Executive is considering legislative change to bring legislation pertaining to disability into line with that in the rest of the UK. However, there is no published timeline or implementation plan.

### **Suggested Question**

**What action is the State taking to remove the identified differences in disability discrimination protection between NI and GB since the introduction of the Equality Act 2010 only into GB?**

## **2.3 Article 6: Women with disabilities**

### **2.3.1 Domestic and Sexual Violence and Abuse**

Evidence suggests that woman with disabilities are two times more likely to suffer physical abuse from an intimate partner than nondisabled women and that disabled women who experience domestic abuse face compound oppressions.

A woman's aid group report that in 2012-13 that of the 880 women who stayed in their refuges across NI, 206 were disabled. Of 44,664 calls to a 24 Hour Domestic and Sexual Violence helpline, 76% of women callers had mental health issues.

Figures are not published for the level of sexual assaults on woman with disabilities.

### **Suggested Question**

**How will the State ensure that programmes and policies to eliminate exploitation, violence and abuse include targeted specific actions to address the issues for woman with disabilities?**

### 2.3.2 Maternity & Screening Services

**“they assume that we can’t think or speak for ourselves, work, have children, need contraception, or smear tests... we can’t have a family, we have a disability, I am not a non-person, they treat us as non-persons.”**

The Department of Health Maternity Strategy makes little reference to the experience of disabled women. Health screenings such as cervical examinations and mammogram screening can be especially difficult with no support, information, available accessible equipment or transport.

### **Suggested Question**

**What actions is the State taking to ensure that women with disabilities have access on an equal basis as others to maternity and screening services?**

## 2.4 Article 7: Children with disabilities

### 2.4.1 Cross-cutting themes for children with disabilities

The Children with Disabilities Strategic Alliance (CDSA) in NI has identified a number of cross-cutting themes that need action to ensure that children with disabilities are able to enjoy their human rights. These include:

- Adequate funding for disabled children and young people.
- Better research and data collection on the needs and circumstances of disabled children and young people.
- Improving access to services.
- Empowering children and young people with disabilities and their families.
- Full and active inclusion of children with disabilities in strategic policy initiatives.

Many of these will be identified in further articles, but in relation to children with disabilities having the right to express their views on

matters affecting them, there are particular concerns.

**“I’m sick of men in suits making decisions about my life – it’s my life – ask me.”**

Whilst there is a strategy and policy in place, often the voice of disabled children is not heard and they have little or no say in how policy and services are developed to meet their needs.

There may be pockets of good practice in some areas but there is not consistency.

### **Suggested Question**

**What action is the State taking to ensure that children with disabilities can express their views on an equal basis as others in respect of the development of legislation and policy which impacts on their lives?**

**What action is the State taking to ensure an effective early intervention is incorporated into its approach to disabled children and young people?**

#### **2.4.2 Children’s Services Co-operation Act**

The Children’s Services Co-Operation Act provides a legislative basis for all departments within the NI to work together to provide a joined up approach to the provision of services to children and young people in NI.

We therefore call for full adherence to this Act, and that it is underpinned within the new Programme for Government and that a new Children and Young Person’s Strategy is completed as a matter of urgency.

In NI there is a lack of strategic direction in relation to the realisation of rights for children with disabilities.

One key area of concern is the lack of data and research in relation to the interventions and outcomes for children with disabilities and their families. There is particular concern over access to early years interventions that, if in place, can have positive outcomes for children and families.

### **Suggested Questions**

**What actions is the State taking to ensure that it effectively cooperates, collects data and demonstrates how its policies and programmes are improving outcomes for disabled**

**children?**

### 2.4.3 Play and Leisure

There continues to be a lack of play and leisure opportunities for children and young people with disabilities due to a lack of mainstream activities that are inclusive and accessible. For example, access to playgrounds with accessible equipment is limited, despite some investment by local authorities.

#### **Suggested Question**

**What action is the state taking to ensure that children with disabilities can access play and leisure on an equal basis as other children?**

### 2.5 Article 8: Awareness-raising

**“Awareness is the most important change”**

**“Advertising campaigns are based in the UK there is a need for local awareness”**

**“There is a lack of knowledge about disabled people’s needs especially in policy areas outside disability”**

During our engagement with disabled people for this report there is a clear message that much more is needed to be done to increase awareness of disability and combat stereotypes.

It is evident that the State must fully understand a rights based approach before developing any future programmes. Messages disseminated by State bodies can have a negative impact on the lives of disabled people (for example, statistical bulletins with level of benefit uptake without any narrative). The State does not provide any strategic direction in demonstrating the positive contribution that disabled people make to society.

The current draft PfG Indicator on disability makes no mention of human rights. The wording and tone highlight the paternalistic attitude to disability that reverberates across Government and society in NI.

The NI ‘Disability Strategy 2012-15’ contains two specific strategic

priorities in relation to Article 8. While action was promised as a in terms of both increasing awareness amongst people with disabilities of their rights and in relation to the promotion of positive attitudes towards disabled people, the ensuing period has seen only sporadic and uncoordinated efforts by the NI Executive.

The draft Action Plan for the quality of life outcome for disabled people in PfG does have specific actions relating to using behavioural change techniques to bring about positive change.

Given the current political situation it is not clear if this will be developed.

### **Suggested Questions**

**What actions are the State taking to ensure that it promotes positive awareness of the capabilities and contributions of disabled people, and what measures are being in place to measure the effectiveness of actions in NI?**

**What actions is the State taking to ensure that people with disabilities gain an increased understanding of their rights and that prevailing negative attitudes towards people with disabilities are creatively challenged and changed?**

### **2.6 Article 9: Accessibility**

**“So many places are still not accessible; people just pass the responsibility to someone else”**

**“Wheelchair accessible transport!”**

#### **2.6.1 Transport**

Access to transport was a key point throughout the discussions with disabled people in developing this report. A new Accessible Transport Strategy is currently in development. There is recognition that there have been improvements, however, disabled people still face unacceptable barriers accessing transport services. The rurality of NI poses particular difficulties. The issue of connectivity is problematic across the board.

### **Suggested Question**

**What is the State doing to ensure disabled people can travel**

**as freely as others?**

#### 2.6.2 Schools

Whilst schools have a duty under SENDO legislation to have an accessibility plan in place, there is no statutory duty for them to carry out the work. It is not just physical access. There is also a considerable lack of accessible information for children with disabilities.

#### **Suggested Question**

**Please ask what the State will do to improve the accessibility of education system for disabled people so that they can access it on an equal basis as others?**

#### 2.6.3 Accessible Information

Accessible information and communication systems remain an issue for people with disabilities.

Disabled people tell us about the lack of access to technology that would make information and communication more accessible to them. Often the high cost of technology can be a barrier, as can a lack of appropriate training.

Information should be available in accessible formats at the time required by disabled people. For example, the PfG Consultation was only made available in Easy Read around 6 weeks into an 8 week consultation period.

There is no monitoring of accessibility of the physical or communication environments. Often whilst policy is in place, there is a large gap between it and the practice on the ground.

#### **Suggested Question**

**What actions is the State taking to identify and eliminate barriers to accessibility, in particular communication barriers?**

#### 2.6.5 Rurality

NI is a largely rural area (around 1/3 of the population live in rural areas). This increases the barriers that disabled people face in accessing a range of services. As outlined above, transport is a key issue. If you can't get to services, how can you use them?

There are also particular issues in the availability of personal assistants in rural areas and access to services for disabled children.

Due to the limited availability of broadband in some rural areas, digital exclusion for disabled people is exasperated.

#### **Suggested Question**

**What action is the State taking to ensure that disabled people**

**in rural areas are able to access services and their community on an equal basis as those living in urban areas?**

## **2.7 Article 10: Right to life**

Several areas of concern were raised in NI in 2012, including health care and organ transplant decision making and access, suicide prevention measures, euthanasia and assisted suicide. This highlighted the inequality of health care due to access difficulties including a lack of accessible information and in relation to the negative value judgements and attitudes towards disability.

Given the lack of robust disaggregated data and research in this area it is unclear how the State can be confident that its obligations under Article 10 are being effectively protected.

In NI we have yet to see the full impact of welfare reform and cuts in social care, but these are slowly beginning to bite, and we are concerned with how disabled people's right to life will be protected.

### **Suggested Question**

**What specific measures are being taken by the State to ensure that any requirements to ensure the full protection of the right to life for all people with disabilities are being addressed?**

## **2.8 Article 12: Equal recognition before the law**

### **2.8.1 Mental Capacity (NI) Act 2016 – Adults**

The Mental Capacity (NI) Act 2016 was given Royal Assent in May 2016, but has not yet been implemented.

This piece of legislation deals with a number of civil and criminal justice matters. Regulations and codes of practice are still in development. There is still considerable concern that the Bill in its current form is not compliant with Article 12. The language in the Bill is still based on 'best interest' rather than 'wills and preferences'. The Minister for Health has stated (24/11/16) that a date for commencement for the Act has yet to be agreed and that it is anticipated that it will take a number of years and will depend on the availability of funding and resources.

The Act gives a statutory right to Independent Advocacy but there is no indication of when this will be implemented. Whilst



Independent Advocacy is available in some health care trusts it is not in all. There is considerable concern that disabled people are being denied their right to make choices about their lives.

This is a significant concern that the delay in implementation will mean that disabled people will still be subject to denial of equal recognition before the law.

Disabled people have told us that it is not just about the law and that other measures need to be taken including training for disabled people, carers, advocates and health and social care professionals.

There is considerable concern that the Act only applies to adults and that there has been no provision made for children with disabilities.

### **Suggested Question**

**What measures is the State taking to provide access to disabled people to the support they may require in exercising their legal capacity (particularly in relation to supported decision making)?**

#### **2.8.2     Mental Capacity Legislation - Children**

Children under the age of 16 have not been include within the Mental Capacity Act in NI. The consultation documents stated that the Mental Health (NI) Order will be retained with amendments. The Children's Law Centre in their briefing on the Bill clearly outlines the issues. The DoH has stated that there would be a separate project to consider children with disabilities. The project was then said to be considered as part a review of the Children (NI) Order 1995. However, at the time of writing there is no evidence of the development of any proposals which will offer children and young people any new legal protections.

### **Suggested Questions**

**What is the State doing to ensure that children and young people under 16 years enjoy the same fundamental freedoms on an equal basis with other children under both article 7 and article 12?**

**What action is the State taking to ensure disabled children and young people are not unnecessarily deprived of their liberty?**

## **2.9 Article 13: Access to justice**

### **2.9.1 Inadequate scope of action to enforce existing disability related anti-discrimination legislation**

Throughout our engagement with disabled people in NI they told us that they believe that there is a lack of enforcement of legislation that is meant to protect them.

Despite disability related discrimination being the single most common equality related complaint made to the Equality Commission in NI, the Commission has the resources to support only a small number of the potential legal actions in this area brought to its attention. With the changes to legal aid (as outlined below) there is a significant risk that people with disabilities will now experience further difficulties in attaining protection under the law.

### **Suggested Question**

**What actions has the State taken to support people with disabilities to have access to due processes to challenge discrimination in NI?**

### **2.9.2 Legal Aid**

The Department of Justice has taken action to reduce the legal aid bill in NI and concerns have been raised about the linkage between a reduction in legal aid arrangements and access to Justice in NI.

### **2.9.3 Accessing criminal justice system**

Progress has been made in NI in improving legal support for the victims, witnesses and alleged perpetrators of crime who have a disability through legislation and codes of practice including the victims charter; the introduction of special measures in the justice system including a registered intermediary pilot scheme; and by addressing the underreporting of disability hate crime through the appointment of a disability hate crime advocate and research.

However, people continue to raise concerns about the limitations of some of these measures. For example, the Criminal Justice Inspectorate concluded that a significant proportion of vulnerable and intimidated witnesses are being excluded from the use of special measures because of poor identification.

### **Suggested Question**

**What actions has the State taken so that disabled people can have equal access to the justice system to attain their rights?**

## 2.10 **Article 14: Liberty and security of person**

### 2.10.1 Prison Services

A 2014 NI Justice report commented that a significant number of prisoners have a psychotic disorder with 25% of women and 15% of men in prison reporting symptoms indicative of psychosis. The rate among the public is 4%. Between 20% and 30% of offenders have learning disabilities or difficulties that interfere with their ability to cope with the criminal justice system.

Two reports in 2013 made recommendations about services in a prison and youth detention facility for prisoners with disabilities, and particularly mental health services.

### **Suggested Question**

**What actions is the State taking to ensure that reasonable accommodation is available to disabled people in prisons in NI?**

### 2.10.2 Deprivation of Liberty

There are concerns that disabled people may be deprived of their liberty due to the lack of suitable community facilities. For example, delayed discharge from hospital due to no available accommodation in the community. Whilst under the law these placements in hospital may be 'voluntary' the fact remains that the reason that the person is still there is lack of suitable accommodation in the community.

### **Suggested Question**

**What actions is the State taking to ensure that disabled people are not unlawfully or arbitrarily deprived of their liberty due to a lack of community services?**

## 2.11 **Article 15: Freedom from torture or cruel, inhumane or degrading treatment or punishment**

### 2.11.1 Health and Social Care

Disabled people have told us about their experiences of inhumane and degrading treatment. This particularly relates to health and social care settings where their care needs have not been met leading to degrading treatment.

A report from the NIHRC Inquiry into NI Emergency Care found that degrading treatment has been experienced, but that it was not systematic.

However, this only relates to emergency care. Disabled people have told us about their experiences of social care. For example, not having a night time call to allow someone to go to the toilet during the night. Instead they were provided with incontinence pads.

Suitable accommodation in the acute hospital setting for disabled people continues to be an issue. Lack of appropriate bathing facilities, trained staff and access to accessible information have led to disabled people experiencing degrading treatment.

### **Suggested Question**

**What actions is the State taking to ensure that disabled people are not subject to degrading treatment in health and social care settings?**

#### **2.11.2 Use of restraint and seclusion**

There is no specific data that we can use for NI. However, our experience through our work shows that whilst use of physical restraint may have decreased, and there are particular policies and procedures in place, that the use of chemical restraint is still ongoing and of concern.

### **Suggested Question**

**What is the State doing to get the use of restraints (both physical and chemically) down to zero?**

#### **2.12 Article 16: Freedom from exploitation, violence and abuse**

##### **2.12.1 Abuse in residential and community settings**

There is no single source of evidence on the abuse of people with disabilities within care systems in NI. The RQIA and the HSCT's along with police all have responsibilities under the Adult Safeguarding Policy. Statistics show in 2014/15 HSCT's received 9,056 adult protection referrals. However, our experience shows us that often the abuse has already happened, what is key is how it can be prevented. For example, the physical and psychological abuse in a care for people with disabilities in Londonderry was only raised after a whistle-blower raised concerns.

### **Suggested Question**

**What preventative policies and measures is the State undertaking to ensure that people with disabilities (including children) are not subject to abuse?**

#### 12.12.2 Hate Crime

Within NI, people with a disability (9%) are three times as likely as those with no disability (3%) to state their lives are greatly affected by a 'fear of crime'.

The latest statistics from the PSNI show that there were 71 disability motivated crimes in the year to 30 September 2016. The reporting of disability hate crime has increased. However, prosecution for disability hate crime is not following the same trend.

### **Suggested Question**

**How will the State ensure that hate crime legislation in NI is effective, particularly in relation to prosecution?**

#### 12.12.3 Human Trafficking

Through their advocacy work, DPOs in NI have encountered situations where it was possible that disabled people had been trafficked for economic and sexual exploitation.

Despite several recent reports on trafficking in NI there is little available evidence on the extent of the problem of the trafficking of disabled people.

## **Suggested Question**

**How will the State ensure that programmes and policies to eliminate human trafficking include including actions to address the issues amongst people with disabilities particularly woman and children with disabilities?**

### **2.13 Article 19: Living independently and being included in the community**

**“Disabled people do not want to be different than everyone else?”**

The recommendations of the CRPD Committee are welcomed by disabled people in NI. To date there has been no response from the NI Executive on the recommendations outlined in the report.

#### **2.13.1 Independent Living Strategic Direction**

Disabled people have told us that this Article is one of the most important, as independent living relates to almost every other Article set out in the UN Convention. Any measure taken by government to undermine the principle and practice of independent living undermines any serious consideration of the Convention.

Whilst the UK State report makes a number of references to policies and programmes to support independent living in NI, this demonstrates its disparate approach.

In NI there has been no attempt to define independent living or develop and deliver a strategy in relation to Independent Living. The NI Disability Strategy has a specific strategic priority in relation to independent living; however, there are no specific actions in the strategy that state how this strategic priority will be met.

The Bamford Report and Action Plan and the Physical and Sensory Disability Strategy both make reference to independent

living, and, in the latter, to the introduction of Choice and Control legislation. In 2009 the Welfare Reform Bill (Part 2) in England and Wales brought forward Disabled People: Right to Control Provision of Services legislation. In NI similar legislation was not brought forward.

NI has not updated its legislation in relation to social care and access to community care since 1978, with the exception of the Direct Payments Act (2002). All three devolved nations have brought forward renewed social care legislation. Whether it affords disabled people any additional rights is yet to be seen, but in NI disabled people have no legislative basis to ensure that they have control over the way social care is delivered.

There are particular concerns that, given the difficult funding

environment in NI, there is a considerable risk that already underfunded disability services will be further impacted by cuts.

Evidence has demonstrated that there has already been a tightening of eligibility criteria, and further examples of when needs are assessed the services are not available. The loss of small scale services, such as help with shopping or paying bills is reducing independence of many disabled people. All too often it is a crisis situation before an intervention is made, and there is a real risk of more people being admitted to hospital based care if community based care is not available.

None of the programmes and policies provided by the State in NI considers independent living in a holistic way. For example, there is little or no co-ordination between education, childcare, transport, housing, employment and social security programmes and policies which if, all working together, would support people with disabilities live independently.

There is currently an expert panel review of Adult Social Care in NI being undertaken by DoH. It is unclear at this stage if any the panel will consider ILF and legislative reform.

### **Suggested Questions**

**Will the State put in place a definition of independent living and provide a legislative basis for the protection of disabled people's right to choice and control in their lives?**

**How will the State ensure that the current reforms of social care in NI increase independent living for people with disabilities and clearly demonstrate and measure a progression the rights as outlined in Article 19?**

#### 2.13.2 Independent Living Fund & Welfare Reform



There is significant concern among disabled people, highlighted through feedback to our questionnaire and conference, that the ongoing impact of welfare reform and the closure of the ILF (to new users in NI) will have a considerable and retrogressive impact on their ability to live independently in their community.

Since the closure of the ILF to new applicants in 2010 there has been no effort to monitor the impact on disabled people who may have otherwise had access to the ILF. ILF in NI has been retained for those already in receipt of ILF but it has not been opened up to new people. There has been no commitment by the NI Executive to open up ILF to people in NI.

Disabled people have also told us that they are concerned about the impact of welfare reform in NI on their ability to live independently.

### **Suggested Questions**

**Does the State intend to open up the ILF to new Users?**

**Does the State intend to ring-fence the ILF budget to ensure that monies are used to support people with disabilities?**

**Has the State undertaken any impact assessment of the impact of welfare reform on disabled people's ability to live independently in their community?**

#### **2.13.3 Resettlement from Long Stay Hospitals and Reassessment and Treatment Units**

Despite resettlement from long stay hospitals being a government priority since 1995, targets set for resettlement have been breached many times since that date. A renewed commitment to resettle all individuals with a learning disability from hospital by 2013 was not met. A new date for completing the resettlement process by 2015 was set, and, once again, missed. As at the 31 August 2016, 107 patients were still resident in Muckamore Abbey Hospital. People with a learning disability continue to remain in hospital, even though they no longer need treatment and could be resettled into the community. Funding has not matched the levels identified as being needed in the Bamford Review of Mental Health and Learning Disability to support resettlement.

There is also concern about disabled people staying long term (2 years+) in assessment and treatment units. These units are meant to be for short term placements, but for a number of reasons, there

have been delays in discharging people into the community.

### **Suggested Question**

**Please outline what action the State is taking to ensure that people with learning disabilities currently living in long-stay hospitals & assessment and treatment units in NI will be guaranteed access to community services and facilities on an equal basis as others, and that these are responsive to their needs.**

#### **2.14      Article 20: Personal mobility**

##### **2.14.1 Travel Training**

It is not just physical barriers which people with disabilities encounter in personal mobility, in particular for people with a learning disability there are psychological barriers. Initiatives such as independent travel training are available but availability is sporadic.

### **Suggested Question**

**What provision is the State making to ensure that people with learning disabilities have access to appropriate training and support to promote independent travel?**

##### **2.14.2 Assistive Technology, Aids and Equipment**

Access to assistive technology can be costly for people with disability. Although schemes such as Access to Work can help for people in work, there is no similar scheme for people who are not working or who can only use their equipment in work or school. Health Trusts may make funding available for communication aids but are less likely to fund computer equipment. Very often people are therefore left to rely on charity to try and raise funds for vital equipment.

Aids and Equipment are generally supplied by the HSCT and there are a range of regional and local services, for example, the regional wheelchair service. However, some disabled people have experienced long waiting times for the appropriate aid or equipment. For example, waiting nearly one year for an appropriate shower chair to be provided.

### **Suggested Question**

**How will the State ensure that people with disabilities have access, in a timely manner to aids, equipment and technology that is suitable for their needs in NI?**

#### 2.14.3 Driving Theory Test

Disabled people have told us about the difficulties they experience in using the current technology used for the theory test. It does not allow for reasonable adjustments for disabled people and therefore is discriminatory in its application.

#### **Suggested Question**

**What actions will the State take to make the theory test accessible to disabled people?**

#### 2.14.4 Impact of PIP on personal mobility

Whilst the impact of welfare reform is only starting to happen in NI we already have evidence of disabled people losing access to the Motability Scheme as a result of PIP. This is having a significant impact on their personal mobility.

#### **Suggested Question**

**What actions is the State taking to ensure that those who lose entitlement to the Motability Scheme do not experience a retrogressive impact on their personal mobility?**

### 2.15 **Article 21: Freedom of expression and opinion, and access to information**

**“Need to be aware of those who do not have social media”**

#### 2.15.1 Accessible Communication Standards

Accessible communication continues to be a barrier to disabled

people in NI accessing their right to freedom of expression and opinion.

There are no accessible communication standards in NI. While some public agencies have guidelines in place, they are not mandatory and rarely monitored.

Alternative formats are currently being produced by a very limited number of groups. This is a negative situation as it creates a backlog in processing requests for information to be produced in the required alternative format. Therefore there should be an increase in the number of providers who are authorised to undertake this vital work.

Accessible communication is a significant barrier to health and social care, and has an impact on Article 22 and the right to privacy.

### **Suggested Question**

**What will the State do to enforce the DDA requirements of information accessibility (including alternative formats) from publishers generally?**

#### **2.15.2 Digital Services**

People with disabilities in NI being less likely to access the internet than their counterparts in the rest of the UK. There is a push for more digital service in Government and it must ensure that disabled people are able to access this on an equal basis.

### **Suggested question**

**What actions will the State take to ensure that disabled people are able to access digital services on an equal basis as others?**

#### **2.15.3 Sign Language**

In NI there are two recognised sign languages, Irish Sign Language (ISL) and British Sign Language (BSL). There are currently 15 fully qualified interpreters in NI serving a population

of approximately 5000 sign language users and the thousands of people they communicate with.

### **Suggested Question**

**How will the State ensure that there is adequate provision of British Sign Language and Irish Sign Language interpreters in NI?**

#### **2.16      Article 22: Respect for privacy**

Lack of accessible communication in health and social care, as highlighted in Article 21, continues to impact on the right to privacy of people with disabilities.

All too often people with disabilities rely on families or friends to help them access health and social care information. This means that they do not have the same level of privacy as their non-disabled peers.

Another recent example is of a person requesting that their information be sent to them by email so that they could access it as they couldn't access printed information. The Health Trust stated that they could not do this due to Data Protection legislation. The fact that giving the information in printed format would have meant the person having to get someone else to read the information, and therefore remove the privacy, was completely overlooked.

### **Suggested question**

**What action is the State taking to ensure that disabled people have access to this information in accessible formats so that their right to privacy is protected?**

#### **2.17      Article 23: Respect for home and the family**

##### **2.17.1 Being a Parent**

Talking to disabled people has highlighted the difficulty in parents with a disability accessing the appropriate support to raise their family. In a number of cases, rather than offering the appropriate supports the first reaction has been to remove the child from the

parent. There are also cases where social services have been present, purely on the basis of a parent having a disability. Unfortunately a lack of disaggregated data does not allow for the development of a sound evidence base.

### **Suggested question**

**What action is the State taking to ensure that parents with a disability have access to the appropriate support to raise their family on an equal basis as others?**

#### 2.17.2 Short Breaks / Respite

Families continually and repeatedly stress the inadequacy of short break provision, with families not getting as many breaks as they need; for as long as they need it; or when and where they need it.

Despite short breaks being identified as a priority by the government, the lack of information about what is available; complex and non-transparent processes for accessing and being eligible for short break support; as well as gaps in short break support as young people move from children to adult services add to the stresses experienced by families in getting the support they need.

There is a real need for a mechanism for Trusts to share provision across areas.

### **Suggested Question**

**What actions is the State taking to ensure that children and young people with disabilities are provided with facilities and get access to adequate short-breaks provision?**

#### 2.17.2 Transition to Adulthood

There is a lack of information for young people and families about the options available, as well as difficulties in identifying the right level and range of services and support for young people to “transition” and move into. The funding and sustainability of alternatives to statutory provision, which is often short term in nature, increases the worry and anxiety of families and the young people concerned and affects their ability to plan for their own future and to be in control of their own life.

Numerous reports and policies have made reference to improving

access to information for children with disabilities and their families. The introduction of the Family Resource Website and a wraparound service is a useful tool but still many children and families lack access to basic information that will help them get the support that is available.

### **Suggested Question**

**What is the State doing to measure the impact of interventions in relation to transitions to ensure that the right services are being developed?**

**How is the State directly engaging with children and young people to co-produce services that will meet their needs?**

## **2.18      Article 24: Education**

The Children with Disabilities Strategic Alliance (CDSA) has produced a number of reports that have identified the areas of concern in relation to the human rights of children and young people in education.

Since the enactment of the Special Educational Needs and Disability (NI) Order 2005, and its emphasis on mainstream education, there has been a marked increase in the number of children with disabilities in mainstream education. There are concerns at the lack of resourcing, planning, participation and support available for these children. This has resulted in pupils with disabilities being placed in mainstream education settings that are ill prepared to meet their needs.

Young people with disabilities are faced with extensive barriers in their quest for educational achievement and fulfilment. However, available data on educational outcomes is extremely limited and specific information on disabled children and young people is not consistently collected. This is particularly the case with children who have multiple disabilities. In terms of population, 44% of disabled people have no qualifications compared to 18% of people without disabilities, while 12% of people with disabilities have a higher education qualification compared to 26% of people without disabilities.

### **Suggested Question**

**What action is the State taking to improve the educational attainment levels of children and young people with disabilities?**



### 2.18.1 Assessment and statementing of children with special educational needs

A delay in assessing need has a significant impact on a child's educational experience, and may leave schools struggling to provide adequately for a child's needs. Inadequate numbers of educational psychologists coupled with a lack of statutory time limits in relation to the school based stages of the process has resulted in unacceptable waiting lists regionally.

The CDSA published further research on 'The State of SEN Statements'. The principal reason for the production of the report is "CDSA's recognition that the statutory process for identification, assessment and provision of services for children with disabilities and SEN is becoming increasingly operationally deficient, primarily as a result of a systematic failure to specify and quantify provision in Statements".

"The lack of quantification can also undermine the protections and rights built into the SEN System for parents to be consulted and their right to appeal to the Special Educational Needs and Disability Tribunal (SENDIST)."

#### **Suggested Question**

**What action will the State take to ensure that children and young people with disabilities in NI have access to appropriate and timely support and interventions to facilitate their effective education?**

### 2.18.3 Training of teachers

We are concerned about the extent and adequacy of ongoing training of teachers of the deaf and visually impaired. Currently, such training is not provided in NI, but rather teachers have to go to England to train and often those teachers remain outside of NI upon completion of their training. There is a real risk of the availability of suitably trained teachers as many have retired or are planning to retire.

#### **Suggested Question**

**What is the State doing to ensure that it has enough fully qualified teachers and auxiliary staff to facilitate disabled children, including children who are sign language users and/or Braille, to access education on an equal basis as others?**

## 2.19 Article 25: Health

**“Health cuts have a major impact on people with disabilities who need constant medication and treatment in order to function on a daily basis and have been told that treatment is being cut due to cost”**

There has been no significant work to understand the health inequalities of people with disabilities that are specific to NI. Data and publications tend to measure health inequalities in relation to the level of deprivation and rural versus urban areas. In 2007 there was data produced in relation to a number of equality groups that considered the mortality rates.

The data from the 2001 Census indicates a 130% higher elevated Age Standard Mortality Rate (ASMR) for those with LLTI compared with those with no LLTI across both genders.

### **Suggested Question**

**What action is the State taking to ensure that early mortality rates for people with learning and mental health disabilities are reduced and that disabled people have equal access to health and related services?**

#### 2.19.1 Access to health services

The Department of Health Access to Health and Social Services in NI document states “that people with disabilities have diverse identities and it is evident that they do experience a number of common barriers to accessing health and social services”.

The Bamford Review and subsequent action plans made many recommendations into reducing health inequalities experienced by people with learning and mental health disabilities. The action plan stated that “a direct enhanced service (DES) will be created, which includes annual GP health checks (for people with a learning disability) and individual health plan”. The evaluation of the action plan showed that 69% of those known to GP practices had received a health check but that “there appeared to be a low uptake of individual health plans which were designed to ensure that health services were addressed”.

Mental health organisations in NI have raised a number of concerns in relation to Article 25. NI has a 25% higher prevalence of mental illness than England with 1 in 5 adults having a mental health condition at any one time. The Victims and Survivors Commission in 2011 published research “troubled consequences” which evidenced the mental health impact experienced both by specific groups and communities and by the whole population; the high levels of Post Traumatic Stress; and the trans-generational mental health impact of the conflict.

There are significant concerns about the disparity in funding for mental health services in NI.

There are also problems with access to GP practices in NI for people who are deaf, hard of hearing, blind or partially sighted. The joint RNID/RNIB/BDA report on access to GP practices shows that there are concerns about accessibility.

There is no data that provides robust indications of access to early intervention or interventions to minimise and prevent further disabilities. However, one of the key areas that has been raised through our engagement process is access to the appropriate drug treatments for conditions like MS and availability of support services such as physiotherapy and speech and language therapy.

In particular there is a disparity across the UK in relation to access to specific drugs or treatments.

Particular focus must be placed on the transition from adult services to older people's services. The current situation in NI is unacceptable as it sees the person who is transitioning to older people's services losing communication with health care professionals who know and are known by the person in question.

### **Suggested Question**

**What action is the State taking to reduce the health inequalities for disabled people in NI?**

#### **2.19.2 Transition to Older Peoples Services**

Transitions also sees a potential reduction in the level of service provided to the person in question.

There are also particular problems in this regard to rural issues, and especially access to health services in rural areas. The proposed restructuring of health services in NI could mean that services (and in particular specialist services) only being available in one geographic area. There is little evidence of how the State will ensure that disabled people are not disadvantaged by this and that appropriate measures are put in place (such as transport provision).

### **Suggested Question**

**What action is the State taking to ensure that people have choice and control over their care, and who provides it, regardless of their age?**

#### **2.19.3 Staff Training**

There is a lack of effective training to staff to ensure that they can meet the needs of disabled people in all areas of services.

### **Suggested Question**

**What action is the State taking to train health care staff to ensure the rights of disabled persons to health services?**

#### **2.19.4 Do Not Resuscitate Orders**

Finally, there is a problem with “Do Not Resuscitate” notices being placed in the hospital notes of people with learning disabilities, without their knowledge or consent. This is unacceptable and must be ceased immediately.

### **Suggested Question**

**What action is the State taking to ensure that disabled people are involved in all the decisions about their health care?**

#### **2.20      Article 26: Habilitation and rehabilitation**

In NI there are a number of impairment specific programmes which provide a range of services. There is concern however, that that access to services can be time limited due to resources or people are waiting for long periods before being able to access services.

There are concerns about how different areas of service interact to ensure that people have access to the appropriate services at the right time.

Parents of children with sight loss have raised specific concerns about access to habilitation services for children and young people. In a report from Blind Children UK research showed that 54% of children with a visually impaired child up to four years did

not receive any help to develop their child's co-ordination.

England has already passed legislation for the provision of habilitation services and Scotland is due to legislate. However, in NI there is no statutory right to habilitation services for children and young people.

### **Suggested Question**

**What action is the State taking to ensure that children and adults with disabilities will have access to appropriate habilitation services?**

#### **2.21      Article 27: Work and employment**

**“There is a gap between training and employment”**

**“Jobs for people with disabilities is key to inclusion in Society and giving a better quality of life”**

The UK report NI's contribution to it, comments that there is a range of vocational and pre-vocational programmes to meet the needs of disabled people. Concerns have been raised about the impact of Brexit on these programmes which are largely reliant on European funding.

Despite the positive report by the State, concerns have been raised in relation to the continuing high employment gap between disabled and non-disabled people. In NI this gap was 38.4%; 55% of people with disabilities are economically inactive compared with 18.7% for those without disabilities.

**"Work is important to us"**

An analysis of factors affecting the employability of people with disability in NI concluded that was a complex range of factors including the attitude of employers, workplace accessibility including transport; a lack of qualifications and skills notably for disabled people leaving compulsory education with low qualifications; personal attitudes towards work, financial incentives; a lack of policy integration and joined up thinking in service provision and the availability, sustainability and the quality of the employment. Remedial action will require the coordination of policies across a range of government departments.

**"Can't get work because I am seen as a health and safety liability!"**

Into work services, such as Steps to Success, suffer similar shortcomings to the Work Programme provision across Great Britain. The threat of benefit sanctions and mandatory participation in often inappropriate services will not address the well documented barriers faced by disabled people. Frontline services are also diminished here by the move away from the specialist Disability Employment Advisor service.

Disabled people have benefited from the retention of smaller scale specialist employment programmes in NI such as Workable. The Department for Communities has in place an Employment Strategy for People with Disabilities which, for the first time, recognises the Supported Employment approach. It includes a specific action plan proposing a range of programmes and policy changes including increased support for people with disabilities. Resources are limited to deliver on this positive strategy and action plan.

### **Suggested Question**

**In the light for the higher incidence of disability and the higher levels of both unemployment and economic inactivity, what actions will the State take to improve equality of outcome in employment for disabled people in NI, and how will it be resourced?**

#### **2.22      Article 28: Adequate standard of living and social protection**

**“My disability isn’t going to change - it’s life-long and progressive – why should I have to go through the trauma of being re-assessed for PIP?”**

**“I’m not a scrounger – people don’t understand how expensive it is to live with a disability – all I want is to live the same way as everyone else.”**

The recommendations of the CRPD Committee are welcomed by disabled people in NI. To date there has been no response from the NI Executive on the recommendations outlined in the report.

##### **2.22.1 Welfare Reform**

One of the key areas of concern that disabled people have told us about is the impact of the welfare reform on their lives.

People with disabilities have told us that they believe the reforms will have a detrimental and retrogressive impact on their ability to

live independently and will also impact on their health.

Whilst Social Security is a devolved matter in NI it operates under the principle of 'parity' with Westminster in relation to social security matters. Despite clear evidence in the NI Executive own Equality Impact Assessment, that Welfare Reform would negatively impact on the lives of disabled people, the Welfare Reform Act is currently being implemented in NI.

A number of elements of the Act are not yet implemented but managed re-assessment of DLA to PIP began recently (Dec 2016).

The proposed transition from DLA to PIP will result in loss of income for many disabled people. It is estimated that in NI over half those in receipt of DLA will either lose their entitlement all together or have their disability benefit decreased.

The NI Executive has put in place a 'mitigations' package until 2020 to 'protect' people from some of the impact of welfare reform.

This includes a specific helpline and face-to-face advice and supplementary payments if a person loses entitlement to benefit.

As welfare reform is only now being implemented in NI we have yet to see how the mitigations package will support disabled people. We are also concerned about what support will be available post 2020.

The mitigations package also does not take into account the impact of stressful assessment processes on disabled people's health and lives.

The impact of welfare reform is likely to be higher in NI. For example, NI has a significant number of people in receipt of DLA per head of population than any of the other nations.

There are concerns that Assessment Centres are not accessible and that this is intentional so that the person is found to be more mobile than reported as they have been able to attend. There are particular concerns about the accessibility of communications in relation to the assessment process.

### **Suggested Questions**

**What action has the State taken to ensure that there is no retrogression of disabled people's rights to an adequate standard of living as a result of welfare reform?**

**What action has the State taken to monitor the impact of welfare reform on disabled people (not just in terms of financial impact but on health and wellbeing)?**

**Why is the State not exempting disabled people with life-long**



## **conditions from the assessment process?**

### **What is the State doing to ensure assessment centres and communication are accessible to all disabled people?**

#### 2.22.2 Impact of Sanctions

Research by the Right to Work: Right to Welfare Group at PPR has monitored the impact of sanctions over three years. They found that “21,000 sanctions were imposed upon claimants last year (2015) without due process or protection from destitution”. Evidence has demonstrated that sanctions are being used for disabled people and those with long-term conditions. The Group made a range of proposals that the NI Executive could implement to deal with the issues. These included due process, improvements to the WCA and a robust risk assessment before implementing any sanction.

Evidence from people includes people being sanctioned on a mandated work programme that they did not know they were on.

Often the information has not been made accessible to people with disabilities so they have not known what they are required to do. There is a clear lack of knowledge of front line staff of the risks associated with implementing a sanctions.

### **Suggested Question**

### **What is the State doing to stop the sanctioning process impacting on disabled people’s human rights?**

#### 2.22.3 Poverty & Disability

People with disabilities in NI are already experiencing poverty, and there are a number of evidence bases for this.

85% of families where there was one or more disabled child had gone without something because of lack of money. This included food, heating, clothes, days out and equipment. A significantly higher percentage of families had gone without heating compared to other regions in the UK.

Fuel poverty is a key concern in NI with a significantly higher percentage of people here experiencing fuel poverty. According to official statistics 42% of households in NI in 2011 were experiencing fuel poverty, one of the highest rates in Western Europe. People with disabilities are recognised as being one of the key groups experiencing fuel poverty.

A report from the Joseph Rowntree Foundation found that: 'Poverty is based on a household's income level so it includes income from earnings but also from benefits such as the disability-related benefits of Disability Living Allowance (DLA) and Attendance Allowance (AA). A much higher proportion of families receive DLA or AA in NI (20 per cent) than in the rest of GB (13 per cent). These benefits are intended to help towards the additional costs associated with having a disability. It can therefore be argued such income should be excluded when calculating if a household is in poverty. If such an approach were taken the poverty rate in NI would increase from 22 per cent to 24 per cent, the largest rise of any part of the UK, and the highest rate of anywhere outside London' <sup>88</sup>

### **Suggested Question**

**What is the State doing to measure and reduce poverty experienced by disabled people and their families?**

**What action is the State taking to ensure that disaggregated data is available on poverty for people with disabilities in NI and that such measures do not include disability related benefits as income?**

**Given the higher rates of poverty experienced by people with disabilities in NI, what action is the State taking to ensure the impact of welfare reform will be monitored to ensure that there is not retrogression of poverty levels?**

**What action is the State taking to reduce the levels of fuel poverty experienced by people with disabilities in NI?**

#### **2.22.4 Housing**

**"Why do disabled people have to struggle to get housing aids and services?"**

Existing social housing tenants will be exempt from the Spare Room Subsidy (until 2020) through the mitigations package. It is clear from evidence that disabled people in NI would be disproportionately impacted by the Spare Room Subsidy for a number of reasons.

Despite significant improvements to the provision of accessible housing there is still no register of accessible social housing or record of social housing where adaptations have been made to a property.

Waiting times for housing adaptations are currently around two years and the system for private households is means tested.

There is concern about the Supporting People Programme in NI as funding has been 'frozen' for a number of years. The programme provides vital support to ensure that disabled people can live independently.

### **Suggested Question**

**What is the State doing that disabled people have access to appropriate public housing, within adequate timescales, and that will meet their needs?**

**What is the State doing to ensure adequate funding for supporting people funding for disabled people?**

**What is the State doing to ensure that disabled people have accessible housing, particularly in relation to the impact of the implementation of the Spare Room Subsidy (Bedroom Tax) post 2020?**

## **2.23      Article 29: Participation in political and public life**

**“Why are there not more disabled people in public office?”**

**“Need opportunities to get our voices heard”**

**“Ask the experts first, us!”**

We believe a range of issues are undermining the full and effective participation of people with disabilities in public and political life in NI. This is one of the main issues raised by disabled people and as it means a complete lack of visibility of disabled people within decision making processes. Such a lack of visibility in turn contributes to the continuing existence of stereotypes and negative attitudes concerning the capabilities of disabled people.

Specifically, there are five key areas:

Consultation processes by statutory agencies with people with disabilities concerning the development of policies and services in NI are, with a few notable exceptions, on a spectrum ranging from the deeply flawed to non existent. Where there is such consultation

it is frequently characterised by:-

- Efforts to engage with people with disabilities that are instigated too late in the consultation process to meaningfully inform and influence it;
- Inadequate provision of information in accessible formats;
- Being facilitated without reference to, or any real knowledge of, the Convention;
- Being conducted within a context in which subtle, and not so subtle, negative attitudes towards people with disabilities are an ingrained and institutionalised part.

There is a very significant underrepresentation of people with disabilities on the Boards of public bodies in NI, with only 2% of the people occupying the 1,400 seats on such Boards having a disability. This is highly significant, as such Boards provide the governance, strategic direction and highest level of decision making of a wide range of statutory sector bodies.

Whether as voters or prospective candidates for election, the electoral process in NI falls short of being inclusive of people with disabilities. Political parties in NI are all too frequently failing to make their broadcast, hard copy and digital communications accessible to people with disabilities. The Access to Elected Office Fund was only ever available to Westminster Candidates. There has been no equivalent fund for NI Assembly Candidates.

### **Suggested Questions**

**What action does the State take to ensure that people with disabilities can fully participate on an equal basis in the development of policies and programmes?**

**What action does the State plan to take to meaningfully address and correct the underrepresentation of people with disabilities on the Boards of public bodies in NI?**

**What action is the State taking to ensure the full accessibility of the electoral process for people with disabilities?**

**What action will the State take ensure people with disabilities in NI have access to funds such as the Access to Elected Office Fund?**

## 2.24 **Article 30: Participation in cultural life, recreation, leisure and sport**

**“I got mocked one evening so I don’t go out in town now, it put me off – they starting signing and copying me shaking, it was in (a well-known bar in Belfast). It was my first time and last time there.”**

In NI evidence shows that people with a disability are less likely to attend arts events than those without (59% compared to 87%) and that 25% of those with a disability participated in an arts event compared to 31% of those without a disability. The proportion of adults with a disability participating in sport, when walking for recreation category is excluded, fell from 32% in 2011/12 to 26% in 2012/13 and people with disabilities are less likely (9%) than those without a disability (26%) to be members of a sports club.

The evidence suggests that not only must facilities and access issues be addressed by the State but the other elements needed to facilitate participation.

Only 3% of people employed within the creative industries in NI have a disability.

### **Suggested Questions**

**What action is the State taking to increase participation in sports and arts activities?**

**What action is the State taking to facilitate employment of disabled people in the creative industries?**

#### 2.27.1 Article 30(4)

The equal treatment of deaf culture and language under Article 30 (4) of the Convention has been an issue of longstanding concern within NI. Following a campaign British Sign Language (BSL) and Irish Sign Language (ISL) used by some of the Deaf community in NI were formally recognised as languages in 2004, following similar recognition of BSL in Great Britain. While this change is welcomed, concerns have been expressed that the change in the status of the languages have had insufficient impact on the processes and duties of the State in contrast to other minority languages.

### **Suggested Question**

**What measures is the State taking to ensure the recognition support and resource of sign languages and deaf culture on an equal basis with others?**

2.25      **Article 31: Statistics and data collection**

***“Knowledge is power!”***

***“Data is not being gathered at the right point, - earlier intervention- more relevant statistics”.***

This was one of the key areas identified by disabled people both in previous research and through engagement. There is a complete dearth of data in relation to disability in NI, demonstrated by the lack of indicators developed by the NI Executive to measure the impact of policies and programmes on disabled people’s lives.

At the launch of the NI Disability Strategy, a baseline was developed by the OFMDFM Research Branch using data derived from the 2006 NI Survey of people with Activity Limitations and Disabilities (NISALD), which examined the prevalence of disability and the experiences of people with disabilities in NI. Additional indicators were also gathered from existing annual surveys and

other administrative sources to allow where possible information against each of the strategic priorities of the Disability Strategy in advance of the intended re-running of the NISALD survey in 2016.

This baseline was further developed through the establishment of a Disability Strategy Monitoring Sub Group in 2013 and engagement was undertaken by this group with the IMNI, academics and a small number of people with disabilities and representative groups; however difficulties were encountered due to lack of funding to cover the additional costs of engagement with some people with disabilities.

**The State never published a set of indicators for the Disability Strategy, and the strategy is due to end in March 2017.**

Under the draft Programme for Government (PfG) there is a commitment in the draft Action Plan for the disability indicator to develop new data sources to measure the quality of life of disabled persons. However, given the political uncertainty at the time of writing it is not known if this will continue under the new Executive. Whatever the outcome there is still a dearth of data on disability available in NI.

The absence of statistics and data in NI on the experiences of people with disability in society negatively affects the formulation, implementation, monitoring and evaluation of policies and programmes to give effect to the Convention and some examples have been referenced throughout this report. Those statistics which are available rarely provide the range and disaggregation of information required to monitor the Convention and/or are not generally accessible to disabled people and their representatives.

Difficulties have also been found in obtaining disaggregated data on people with disabilities in NI from UK national studies in which, while the disaggregated is often collected it is rarely published.

This is particularly important when responsibility for the Convention obligations has been retained at UK level or where a comparison between UK regions would add to the monitoring process. This data can sometimes be obtained from the State body responsible but at a cost can be applied.

Co-ordinated action is required to be undertaken by the State with the participation of disabled people in order to resolve the current situation in relation to both the nature of the statistics and data collected and its accessibility.

### **Suggested Questions**

**How will the State develop indicators that will relate to the UNCRPD and be comparable against other devolved nations and internationally (and be inclusive of children and adults with disabilities)?**

**What measures has the State taken to ensure that all information collected under Article 31 is accessible to persons with disabilities?**

#### 2.26.1 Low Awareness of the UNCRPD Convention

There is a very low level of awareness of the Convention amongst people with disabilities in NI, meaning that, in the Context of Article 33, the levels of participation and engagement by disabled people that should lie at the heart of its implementation are impeded.

Research by the Equality Commission NI found that only 21% of people with disabilities in NI had heard of the Convention. It is likely that those with a sufficiently developed understanding of the Convention to enable their active participation in its implementation and monitoring are considerably lower than this awareness figure.

While responsibility for developing disabled people's awareness and understanding of the Convention lies solely with the State, it is undeniable that the lack of resources available to IMNI has meant that it has not been in a position to undertake the level or extent of its duties to promote, protect, and monitor the implementation of the Convention as was expected on the ratification of the Convention. In this context, it is instructive to note that, as far as we are aware, the only additional resources made available to the Equality and Human Rights Commissions in NI to underwrite the work of IMNI consisted of a one off grant from the ODI comprising of £10,500. Against this backdrop, it becomes entirely understandable why our direct engagement with a wide spectrum of people with disabilities leads us to believe that the percentage of

disabled people who are aware of IMNI's role and function is very low indeed.

**“The IMNI need more resources to promote the convention”**

#### 2.26.2 Participation of Civil Society and Persons with Disabilities

Within NI, DPOs acknowledge the efforts of the IMNI within limited resources to perform their role under Article 33(2) and to engage with people with disabilities and DPOs through seminars, conferences, events and research. IMNI recognised the need for engagement in their Article 33, 'Framework document' however, we are not aware of any formal structure within the IMNI to consult and work closely with disabled people and DPOs specifically in relation to their 33(2) duties in order to develop priorities for action and monitor the Convention.

Research for this paper also found that specific knowledge of the IMNI and the Convention reporting processes was also low, with people with disabilities, their organisations and other stakeholders reporting that they had not heard of either.



**“What is IMNI? Who are they?”**

**“Is there a good robust monitoring mechanism in place and is this being communicated?”**

This lack of awareness has resulted in a lack of engagement with the process beyond the ‘usual suspects’. People with disabilities and their organisations suggested some actions to be taken.

**“Greater transparency about how they (IMNI) operate”**

**“More communication”, “need for updates”**

**“Greater engagement with people with disabilities and disability organisations”**

The capacity of DPOs to be actively involved in the implementation and monitoring of the Convention has decreased in some cases due to diminishing resources.

In Scotland, England and Wales funding was made available to DPOs through a tender process to engage with disabled people and produce a shadow report for each Nation. No funding was made available in NI. This has meant less engagement with disabled people and a complete lack of resource to update the 2015 report. It has relied on the goodwill of many people to provide their time and resources in developing the report.

What it highlights completely is the lack of any government strategy to strengthen DPO’s in NI and support them to undertake work like shadow reporting.

In these stringent economic times, unless Government supports the capacity building and resilience of people with disabilities and DPOs to engage with the Convention, the active participation and involvement by disabled people envisaged by the Convention will remain greatly diminished.

## **Suggested Questions**

**What additional resources have been made available by the State government for the processes required under Article 33 UNCRPD?**

**What structures does the UK have in place to ensure the close consultation with and active involvement of people with disabilities, including children with disabilities, through**

**their respective organisations at a national level and devolved level in Scotland, Wales and NI in relation to its duties under Article 33?**

**What is the State's strategy to increase the capacity of people with disabilities and Disabled Peoples' Organisations to be actively involved with structures and procedures of the Convention?**

**What financial and capacity building resources will the State provide to Disabled Peoples' Organisations?**

### **3.0 Impact of the UK vote to leave the European Union ("Brexit")**

During 2016 we undertook engagement to understand what the key concerns are in relation to disability and Brexit.

During discussions with disabled people and their organisations three main areas that require consideration arose, and these are outlined below.

- 1) No retrogression of rights and protections currently available under EU Law.
- 2) Funding – protection for existing programmes and identification of new sources of funding for programmes funded under EU Funds.
- 3) The involvement of disabled people and their organisations in Brexit decision making.

In particular there are concerns about retrogression of employment rights and human rights.

### **Suggested Question**

**What is the State doing to stop any retrogression of the rights and support afforded to disabled people in NI by virtue of their currently being citizens of the EU following "Brexit"?**

### **Ends**

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## **Endnotes**

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