



**Response to the Autism Strategy (2013 - 2020) and Action Plan
(2013 - 2015)
Department of Health, Social Services and Public Safety (DHSSPS)**

Introduction

1. Under Article 33(2) of the United Nations Convention on the Rights of Persons with Disabilities (CPRD), the UK Government designated the four equality and human rights commissions to make up the UK's Independent Mechanism. In Northern Ireland, the Independent Mechanism is represented by the Equality Commission for Northern Ireland (ECNI) and the Northern Ireland Human Rights Commission (NIHRC), hereafter referred to as the Independent Mechanism for Northern Ireland (IMNI).
2. IMNI is the 'independent' element within the framework, established by the State Party, under Article 33(2). IMNI has clearly defined and separate roles and responsibilities from those of the State Party and civil society, to promote, protect and monitor implementation of the Convention in Northern Ireland.
3. This submission has been drafted jointly by the Equality Commission for Northern Ireland and the Northern Ireland Human Rights Commission in furtherance of their role as IMNI.
4. The UK ratified the CRPD in 2009. At its core the CRPD seeks to promote, protect and ensure full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their dignity. Persons with disabilities should be able to enjoy the same human rights as everyone else and be able to lead their lives as full citizens who can make a valuable

contribution to society. It is a unique Convention with an explicit social development dimension.

5. It provides a holistic framework which Government can rely upon to develop a human rights based approach to the issues facing disabled people in Northern Ireland. A 'human rights based' approach acknowledges that if something is necessary for a person to live in dignity, then it is a right that can be claimed and thus the Department must do everything it can to honour its obligations under the Convention in that regard.
6. The CRPD therefore provides an invaluable framework which policy developers should rely upon in developing strategies and policies for persons with disabilities in Northern Ireland.
7. IMNI broadly welcomes the Strategy and in particular, the recognition given to CRPD. In setting out our views, we have highlighted how the Strategy can be further strengthened to ensure respect for the rights guaranteed by the CRPD.
8. Our comments on the Strategy focus on the strategic priorities and the delivery framework, taking account of the respective remits of both Commissions and the views of a range of stakeholders, including disabled people and their representative organisations.

Multiple Identities of Disabled People

9. It is important to recognise that people with autism come from a wide variety of backgrounds and have identities and interests beyond their disability. The CRPD highlights the fact that disabled people are often subject to multiple or aggravated forms of discrimination on the basis of race, colour, sex, language, religion, political or other opinion, national, ethnic, indigenous, or social origin, property, birth, age or other status (e.g. sexual orientation)¹. The Convention reminds us of the importance of taking into account the multiple identities of disabled people.

¹ Preamble, paragraph (p).

Accessibility

10. The Independent Mechanism welcomes the reference to Article 8 of the CRPD. The consultation paper acknowledges that 'negative attitudes and perceptions that exist about people with autism can add to the barriers which they face in their everyday lives'. Article 19 of the CRPD protects the right to live independently and be included in the community, and states that:

'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 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'.

11. We are aware that that the negative attitudes and perceptions of some persons or groups may present a barrier to participation in community services and facilities by those with autism. IMNI advises that this is acknowledged in the Strategy.

Data Collection and Research

12. We note the intention to collect, record and report autism prevalence data. Article 31 of the CRPD states that countries must collect appropriate information, including

statistical and research data to enable them to formulate and implement policies to give effect to the Convention. We recommend that a specific reference be made to Article 31. Data collected under the autism strategy should be collated along with statistics & data being collected under the NI Executive Disability Strategy - '*A Strategy to Improve the lives of people with Disabilities 2012 - 2015*'².

13. We recommend that the Department and other public authorities align specific measures relevant to the Strategy and Action Plan with their Section 75 and Disability Duties Action Plans. The Equality Commission's guidance emphasises the importance of partnership working as a means of enabling delivery on Section 75 and Disability Duties obligations³.
14. In relation to the actions regarding access to information and referrals, we suggest that the Department provide further details about these measures in a quantifiable way and include these in the action plan. In addition the Strategy should set out how these measures relate to and compliment existing commitments outlined in the Northern Ireland Executive's Disability Strategy⁴.
15. We recommend that the Department and other public authorities align specific measures relevant to the Strategy and Action Plan with their Section 75 and Disability Duties Action Plans. The Equality Commission's guidance emphasises the importance of partnership working as a means of enabling delivery on Section 75 and Disability Duties obligations.

² Office of the First Minister and Deputy First Minister (OFMdfM) (24 January 2013): *A Strategy to improve the lives of people with disabilities 2012 – 2015*. Available at: <http://www.ofmdfmi.gov.uk/disability-strategy-2012-2015-revised-010313.pdf>

³ Equality Commission for Northern Ireland (2005): *Practical Guidance on Equality Impact Assessment*, page 11; Equality Commission for Northern Ireland (2007): *A Guide for Public Authorities – Promoting positive attitudes towards disabled people and encouraging the participation of disabled people in public life*, paragraph 3.57, pages 35-36.

⁴ Office of the First Minister and Deputy First Minister (OFMdfM) (24 January 2013): *A Strategy to improve the lives of people with disabilities 2012 – 2015*. Available at: <http://www.ofmdfmi.gov.uk/disability-strategy-2012-2015-revised-010313.pdf>

Children, Young People and Family

16. IMNI welcomes the recognition of the rights of children with autism and their families. The provision of respite care to families is vital. However, we would welcome further clarity on the additional support which the Strategy will provide.
17. We note that the Northern Ireland Commissioner for Children and Young People has called for a statutory 'duty to co-operate' to better facilitate the delivery of joined-up working⁵. We recommend that consideration be given as to how to include disabled children and young people in the development of Government policy initiatives, as well as in measures undertaken in this regard by other public authorities. Such consideration should also take into account the need to ensure that disabled children and young people with autism and their families and advocates are actively involved in shaping and informing the future development and delivery of this Strategy and associated Action Plan.

Independent Living

18. The section of the Action Plan dealing with independent living refers only to the issue of housing. However, facilitation of independent living requires broader consideration e.g. the need for access to a range of support mechanisms, including personal assistance, to support inclusion in the community. The Strategy should fully acknowledge all aspects of the right to independent living and refer to the specific support service provisions which persons with autism may require to enable them to live independently.

Transition

19. IMNI is aware of the need for support for people with autism during transitional periods. We recommend that the Strategy should recognise the transition from adulthood to older age as well as the transition from childhood to adulthood. The Strategy should refer to the current reforms in the adult care

⁵ NI Commissioner for Children and Young People (2011): *Barriers to Effective Government Delivery for Children in Northern Ireland*, paragraph 3, page 45.

system and to specific requirements with respect to the rights of autistic persons.

20. We previously highlighted that the report of the Transitions Inter-Departmental Working Group (2006) identified gaps in transition planning and urged that these were addressed in the forthcoming action plan to implement the Disability Strategy⁶. Since the removal of the Children's Fund, we understand that organisations delivering transition services have faced difficulties in sustaining this provision. The Department and other relevant agencies should give consideration to the resources necessary to sustain transition planning for people with autism.
21. The consultation paper refers to the 'Transforming Your Care' policy initiative, but does not consider in detail potential implications for person with autism. IMNI advises the rights and views of those with autism should be taken on board in the development of this reform initiative. We have drawn attention to CRPD Article 29, the right to participation in political and public life, below. The NI Executive is obliged to fulfill the right to participation for people with autism with respect to any reform proposal which may have significant implications for disabled persons with respect to changes to the health and social care system. It is important that this right is fully realised to ensure positive outcomes.

Employment & Employability

22. Article 24 of the Convention recognises the right of access to both tertiary education and vocational training. Fulfilment of Government's obligation to ensure people with autism have access to education is a vital component to ensuring that they are able to access employment.

⁶ Department for Education, Department for Employment and Learning, Department for Health, Social Services and Public Safety (2006): *Report of the Transitions Inter-Departmental Working Group*. Amongst the gaps identified were inappropriate and inflexible day-care provision for young adults, limited vocational and life skills training opportunities, lack of flexible employment opportunities e.g. open and supported employment, lack of advice and information to parents and young people with disabilities and gaps in transition training for independent living.

23. We welcome the reference to the Department for Employment and Learning's key employment programmes and services to assist people with disabilities to access further and higher education, vocational training and employment. We acknowledge the range of additional measures set out in the Strategy. However, information obtained from our UNCRPD evidence gathering workshops⁷ with respect to Article 27, work and employment, and stakeholder round-tables on the draft Disability Strategy highlighted that mainstream government programmes to support people with disabilities into employment did not include accurate statistics and targets for disabled people with complex needs. The majority of people within this category cannot avail of the more mainstream government employment programmes.
24. Programmes such as Workable NI, Access to Work and the Job Introduction Programme are excellent programmes providing assistance and support as well as technical support (assistive technology support). However, stakeholders at the ECNI CPRD evidence gathering workshops claimed that these do not meet the needs of people with significant disabilities including those with autism. For example, with regard to the Workable NI programme, a key criteria for access to the programme is that the duration of the job must be for sixteen hours or more per week. We are aware that a significant number of people with autism and other disabled people with complex support requirements are unable to meet that level of commitment.
25. We have since been advised that a key criteria for the Work Connect programme is a requirement to be in employment for 8 hours or more. We acknowledge this lower threshold as a positive development. However, we would welcome the extension of state funding for this programme beyond the current 6 months limit.
26. Recognising the need to promote and protect the human rights of all persons with disabilities, including those who

⁷The Equality Commission for Northern Ireland with the Northern Ireland Union of Supported Employment held two evidence gathering workshops on UNCRPD Article 27, Work and Employment, in Belfast during March and April 2011.

require more intensive support, as enunciated in the Preamble, paragraph (j), to the CPRD, we recommend further consideration is given to ensuring that all people with disabilities are given appropriate support to avail of educational, training and employment opportunities.

27. It is estimated that there are 16,000 people in Northern Ireland with autism⁸. The National Autistic Society found that only 50% people with autism in Northern Ireland are in full time employment despite the fact that many can and want to work⁹.
28. Further consideration should be given to what additional measures could be included in the Strategy to support people with autism into mainstream employment programs, including those with complex support requirements.

Welfare Reforms

29. Furthermore, we suggest that greater account is taken within the Strategy of the current welfare reform measures, in order to address potential adverse impacts that may effect people with autism and their families, especially in the present situation of rising unemployment and economic recession. The forthcoming welfare reform measures must be considered within the context of CRPD Article 28, which recognises the right of people with disabilities to an adequate standard of living and obligates states to *'take appropriate steps to safeguard and promote the realization of this right without discrimination on the basis of disability'*. Reduction in disability benefits and lack of employment opportunities may lead to economic hardship, social isolation and exclusion for many disabled people, particularly for those who do not have access to mainstream employment programs.

⁸ <http://www.bbc.co.uk/news/uk-northern-ireland-17578705>

⁹ The National Autistic Society Northern Ireland, the Department for Employment and Learning, the Equality Commission for Northern Ireland and Employers for Disability Northern Ireland (2011): *Employing People with Autism - A Brief Guide for Employers*, final paragraph, page 1. Available at: <http://www.ofmdfmi.gov.uk/disability-strategy-2012-2015-revised-010313.pdf>

30. In our view it is vital that the Strategy takes account of all additional support necessary to enable those with autism to access and gain employment on an equal basis with others. We also recommend that the monitoring framework incorporate arrangements to monitor the impact of welfare reform on those with autism.

Access to Justice

30. IMNI notes the recognition given to CRPD Articles 13 and 16. We welcome the recognition of the importance of adequate training for frontline staff in the justice system. Furthermore, it is important that guidance provided to frontline staff, and in particular the police, takes account of the rights of disabled persons.
31. Noting the example provided within the consultation paper, IMNI would welcome further information on the guidance and support provided to police officers when a person with a disability is the subject of stop and search powers.
32. IMNI wishes to draw attention to the issue of disability hate crime. In 2011/12 there were 15 crimes with a disability hate motivation and 33 incidents¹⁰. However, it is widely believed that the incidence of disability hate crime is significantly under-reported and that there are a number of reasons for this e.g. some disabled people may not understand that they have been the victim of hate crime. IMNI advises that arrangements to assist persons with autism to report hate crime and support them to cope with the consequences of crime are further set out in the Strategy.

Being Part of a Community

33. IMNI notes the acknowledgement given in the Strategy to Article 30, CPRD. IMNI notes that this Strategic priority also relates to access to sport and leisure. In light of the clear linkages between physical exercise and health, IMNI advises

¹⁰ Police Service of Northern Ireland (July 2012): *Trends in Hate Motivated Incidents and Crimes Recorded by the Police in Northern Ireland 2004/05 to 2011/12 Annual Bulletin*, page 11.

that the Strategy include a specific reference to CRPD Article 25, the right to the highest attainable standard of health.

Participation and Active Citizenship

34. IMNI advises that the Strategy refer to CRPD Article 29, participation in political and public life. IMNI notes the positive engagement between the Northern Ireland Assembly and the autism community which occurred during the passage of the Autism (NI) Act 2011. IMNI recommends that the action plan make reference to mechanisms of support within local councils and the NI Assembly to facilitate the participation of autistic persons.
35. In research published by the Equality Commission on behalf of IMNI in 2012, disabled people identified their right to participation in decision-making as a key priority¹¹. We are also aware that Autism Northern Ireland viewed this as key issue to be addressed within the Strategy.
36. The effective implementation of the strategy will continue to require the ongoing engagement and active involvement of disabled people, and their representative organisations, in decision-making, and policy formulation associated with the Strategy (Article 4(3)).
37. We, therefore, very much welcome the proposals regarding the establishment of user groups in each Health and Social Care Trust area to assess progress and provide feedback from a service user/carer/family perspective.

Section 75 and Disability Duty Action Plans

¹¹ Harper, C, McClenahan, S, Byrne, B. & Russell, H. (2012): *Disability programmes and policies: How does Northern Ireland measure up? – Monitoring implementation public policy and programmes of the United Nations Convention on the Rights of Persons with Disabilities in Northern Ireland* (Equality Commission for Northern Ireland: Belfast). Available at: <http://www.equalityni.org/archive/pdf/UNCRPDFullReportFINAL260112.pdf>

38. The DHSSPS and other public authorities involved in the implementation of the Strategy should also bear in mind that effective implementation of the public sector disability duties, under the Disability Discrimination Act 1995 (as amended), together with the public sector duties under Section 75 of the Northern Ireland Act 1998, will also assist in the effective implementation of the Strategy in the long-term, as well as demonstrating further evidence of a serious commitment to CRPD.

Monitoring and Implementation

39. IMNI advises that the actions included within the action plan be reviewed to ensure that they are sufficiently specific and measurable. Furthermore, we recommend that a more detailed timetable should be included.
40. The recent independent research commissioned by the Equality Commission on the implementation of the CRPD in Northern Ireland¹², concluded that the availability of robust data, information and statistics is central to evidence-based policymaking and to an effective monitoring process under Article 33.
41. The research concluded that it was '*currently extremely difficult to measure the effectiveness of public policy in relation to people with disabilities*' and this was '*due to a lack of co-ordinated and effective monitoring to quantify the impact of policy change*¹³.
42. Furthermore, the research found that statistics on policies and programmes were very rarely disaggregated to give information on persons with disabilities or on the type of disability¹⁴.
46. In summary, IMNI welcomes the Autism Strategy and the associated Action Plan. If implemented effectively, the Strategy will address many of the issues and concerns faced

¹² Harper et al (2012), Op Cit.

¹³ Harper et al (2012), Op Cit., page 253.

¹⁴ Ibid, page 254.

by people with autism, their families, advocates and representative organisations. We hope that our comments will serve to assist the Departments tasked with the delivery of the Strategy to bring about tangible positive outcomes for people with autism living in Northern Ireland. For ease of reference our views on the Strategy are further summarised into a number of brief points set out below.

47. The Commission recommends that the DHSSPS and other Departments identified in the Strategy should:
- guarantee the effective participation of people with autism including their representative organisations and their families/advocates in the delivery of the Strategy;
 - ensure that human rights and equality considerations are at the heart of the implementation of the Strategy;
 - take account of the multiple identities of people with autism and their carers e.g. children, young and older people, those belonging to minority ethnic communities etc;
 - include arrangements for the collection of appropriate data;
 - take into account the potential impact of welfare reform and address any adverse effects it may have in relation to people with autism and disabled people more generally;
 - include realistic and meaningful outcome focused targets in the Action plan;
 - include a clear commitment to the allocation of resources to the Strategy;
 - take account of the Northern Ireland Executive's Disability Strategy;
 - ensure that account is taken of those persons with autism with complex and intensive support requirements in the development of mainstream government programmes in relation to employment, education, training and all other measures associated with the strategic priorities.

Annex 1:

The Independent Mechanism for Northern Ireland

The Equality Commission and the Northern Ireland Human Rights Commission are jointly designated as the “Independent Mechanism” in Northern Ireland to promote, protect and monitor the implementation the United Nation Convention on the Rights of Persons with Disabilities (UNCRPD).

The Equality Commission for Northern Ireland

The Equality Commission for Northern Ireland is an independent public body established under the Northern Ireland Act 1998. We are responsible for implementing the legislation on fair employment and treatment, sex discrimination and equal pay, race relations, sexual orientation, disability and age.

The Equality Commission’s remit also includes overseeing the statutory duties on public authorities to promote equality of opportunity and good relations under Section 75 of the Northern Ireland Act 1998 (Section 75) and to promote positive attitudes towards people with disabilities and encourage participation by disabled people in public life under the Disability Discrimination Act 1995.

In addition to its role as Independent Mechanism under the UNCRPD, the Equality Commission’s general duties include:

- working towards the elimination of discrimination;
- promoting equality of opportunity and encouraging good practice;
- promoting positive/affirmative action;
- promoting good relations between people of different racial groups;
- overseeing the implementation and effectiveness of the statutory duty on relevant public authorities;
- keeping the legislation under review; promoting good relations between people of different religious belief and/or political opinion.

The Northern Ireland Human Rights Commission

The Northern Ireland Human Rights Commission is the national human rights institution for Northern Ireland working with other NHRIs all over the world through the international network of the United Nations to protect the most vulnerable and marginalised and ensure the promotion of the human rights of all people in Northern Ireland.

It is the role of the NIHRC to promote awareness of the importance of human rights in Northern Ireland, to review existing law and practice and to advise the government on what steps need to be taken to fully protect human rights in Northern Ireland.

In carrying out this work the NIHRC bases all of its work on international human rights standards, including those of the United Nations (UN) and the Council of Europe, that have been accepted by the United Kingdom. The Commission, in line with the UN 'Paris Principles' guidance of 1993, has 'A' status recognition at the UN as a national human rights institution with access to the Human Rights Council.

Duties and Powers

The NIHRC is an independent public body established by the Northern Ireland Act 1998. Its powers and duties are derived from sections 69 and 70 of the Northern Ireland Act 1998 and sections 14-16 of the Justice and Security (Northern Ireland) Act 2007.