
**Introduction**

Barnardo’s NI is the largest children’s charity in Northern Ireland. We work with almost 11,000 children, young people and families in more than 40 different services and programmes, and in over 150 schools. These range from early intervention programmes and family support to services for disabled children and young people.

Our work with disabled children and their families includes autism support and community services; a disabled children and young peoples’ participation project; training young people with learning disabilities for employment in the hospitality industry; and short breaks and respite care for children and young people with a learning disability. A considerable number of the children and young people we work with in these services have conditions which are on the autistic spectrum.

To help inform policy development Barnardo’s NI regularly engages with children, parents and practitioners. The Autism Strategy and associated Action Plan will impact on the lives of many of the children, young people and families we work with and their experiences form the basis of this consultation response. An individual response has also been submitted by Barnardo’s NI Disabled Children and Young Peoples’ Participation Project (DCYPPP).

**Overview**

Barnardo’s NI welcomes publication of the draft Autism Strategy and Action Plan and its positive emphasis on the values of dignity, respect, independence, choice, equality and anti-discrimination for people with autism. We also support recognition in the Strategy of the need for a ‘whole life’ approach to the provision of services and support.
The Autism Act (NI) 2011 which requires publication of an Autism Strategy also legislates for Government Departments to work together to achieve a more streamlined approach to the provision of services for people with autism and their carers. It is particularly welcome therefore to see this reflected in the Strategy and Action Plan with the move towards a cross-departmental, integrated and collaborative framework for the delivery of autism services in Northern Ireland. It would be helpful however for the Strategy to more clearly link throughout to the wider strategic framework, specifically the range of existing and planned policies and strategies across all NI Executive Departments.

Barnardo’s NI agrees with the strategic priorities outlined in the Strategy and Action Plan. We are however concerned at the general lack of detail and vagueness in respect of the ‘User/Carer Defined Outcomes’ and would recommend inclusion of clear, measurable targets relative to the key actions in each section. There also appears to be some disparity between departmental inputs and Barnardo’s NI recommends that all Departments show requisite investment in the process.

The Strategy outlines the range of services and support currently available to people with autism but also acknowledges there may be limited additional investment. We are concerned that the necessary funding is not in place to deliver what is required to appropriately meet the needs of all children and young people with autism and their families.

While the Strategy highlights some increased investment in children’s services in recent years, it is our experience that this has been targeted primarily at diagnosis rather than intervention and that services are dependent upon diagnosis. Barnardo’s NI therefore recommends that additional resources are made available for the provision of early intervention and family support services pre and post diagnosis.

The Strategy states on p.18 that in health and social care, funding to meet the needs of people with autism has traditionally been included within the Learning Disability programme funding and because of this it is not possible to identify specific expenditure on autism services. This requires clarification as it is difficult to comprehend how autism services can be designed and delivered without knowing how much budget is available. Moving forward it would be essential to clearly
record and publish how funding is broken down and where it is allocated.

Some further information about membership on the proposed Autism Strategy Implementation Group would be welcome, for example, could the Group also include non-statutory representation? Barnardo’s NI recommends an inclusive model with regards implementation of the Autism Strategy in order to continue the collaborative and co-operative approach taken to date in its development. The cross-departmental NEET Advisory Group, tasked with taking forward implementation of the Pathways to Success NI NEET Strategy, includes representation from the voluntary and community sector and in our view provides a good model for how policy development should be taken forward.

Up-to-date and accurate data on the prevalence of autism in child and adult populations is currently lacking in NI and we agree this must be redressed to ensure effective implementation of the Strategy. Barnardo’s NI recommends that those initiatives outlined in the Strategy to capture relevant data and enhance autism research are progressed swiftly to ensure the development and delivery of appropriate autism services here.

It would be helpful to provide some clarification about where the Middletown Centre for Autism sits within both the Strategy and the broader autism network in NI, notably its role in relation to health provision.

Finally, implementation of the Welfare Reform Bill will impact on many people in Northern Ireland, including those with autism and their carers. The Bill introduces Personal Independence Payment (PIP) to replace Disability Living Allowance; the Treasury’s intention is to reduce expenditure on DLA by 20%. This is concerning given that disabled children and their families already experience particularly high levels of economic and social disadvantage. The impact of these changes should be considered as the Autism Strategy is being taken forward. Barnardo’s NI recommends the NI Assembly presses for robust monitoring and reporting arrangements of the impact of the Bill on those affected – claimants, children and carers from the outset.

Additional points - consultation questions

Q2: Barnardo’s NI agrees with the vision, values, aim and objectives for the Strategy as outlined in the consultation document. In addition

**Q3:** Barnardo’s NI agrees with the themes of the Strategy which have been developed in consideration of some of the articles in the UNCRPD. However, we also recommend that education is included as a distinct strategic priority given the critical role of education in developing better outcomes for children with autism. In our view there needs to be better collaboration, sharing of information and support for young people with autism moving from school to further education training or employment.

**Q4 – 12:** As stated previously, Barnardo’s NI generally agrees with the strategic priorities in the Strategy/Action Plan but believes the outcomes associated with each Action lack detail. It is not clear for example how the ‘positive experiences reported by people with autism and their families due to increased awareness about autism’ is going to be effectively measured. We would also make the following additional points in relation to some of the strategic priority areas in the Action Plan:

- **Awareness**

  There is a need for improved awareness-raising amongst professionals working with disabled children and young people in order to gain a greater understanding of the range of diversity of disabilities. The Autism Strategy should specifically link in and complement the awareness raising priorities in the Disability Strategy.

- **Accessibility**

  We believe that some measure of the success of the ‘Six Steps of Autism Care’ departmental pathway would be very helpful at this stage. Barnardo’s NI recommends this programme is subject to review and evaluation.

  (2.2.1) **Improvements in referral systems and procedures from identification to assessment/diagnosis of autism through to intervention:** Early detection and diagnosis is an important first step in the process of providing support and ensuring best outcomes for
children and young people with autism. However, while diagnosis has improved dramatically as a result of the Regional Autistic Spectrum Disorder Network for NI (RASDN), the majority of services provided are dependant on diagnosis. Barnardo’s NI believes that services need to be better at meeting the needs of children and families pre-diagnosis.

Recent research in the Southern Health and Social Care Trust has demonstrated the level of comorbidity of conditions as experienced by children and adults with autism. Barnardo’s NI recommends that both intra and inter agency working needs to be improved in respect of the management of comorbidity. There should also be greater investment in early intervention training for education and health professionals, especially at GP level. Young people with autism consulted by Barnardo’s NI felt that professionals should listen to them and their parents more when it comes to being assessed for autism.

The young people we talked to also thought that teachers in nursery and primary schools should get support and training to enable them to identify and refer a child whom they suspect of having autism to the appropriate service. In their view this should include training on how to approach the subject of autism with parents.

“...new teachers are trained pretty well in autism but older teachers are not” (Young person)

(2.2.2) Appropriate education provision available for people with autism to meet their needs: There is no detail in the document about what constitutes appropriate education provision and this needs to be clarified. Barnardo’s NI recommends that provision in mainstream schools is subject to evaluation, notably in respect of inclusiveness and transition into further education.

(2.2.6) A referral pathway established between criminal justice agencies and HSC Trusts: Barnardo’s NI recommends this section also includes some reference to, and links in with, the development of a new Regional Forensic Health Service. This is important in respect of young people with disabilities, particularly ASD, who are involved with the juvenile justice system.
• Children, young people and family

(3.1.1) **Joint working arrangements between HSC Trust autism services and Education autism intervention and advisory services:** We have some concerns these arrangements will vary between HSC Trusts. In our view robust formal arrangements must be in place early and consistently applied across HSC Trusts. Three year pilot multi-disciplinary Early Intervention Teams in each of the five Education and Library Board areas have been established to identify and assess pupils facing barriers to learning such as learning difficulties. It will be helpful to learn how these are progressing and how they fit within the Autism Strategy and Action Plan.

(3.1.2) **Support provision for families and in particular siblings of children with autism scoped/scaled:** We welcome the inclusion of this output/outcome measure and recommend it is swiftly progressed. To date the majority of support for siblings has been provided by the voluntary and community sector when funds allow. Some voluntary organisations have a lot of expertise in this area which has not been recognised through requisite funding.

Rather than access carer groups, many siblings tell us they would prefer support services/groups for siblings that are specific to autism so they can talk more openly about sensitive issues with other young people in similar circumstances. In our experience siblings should be engaged in groups from a young age and also more involved in activities being undertaken with autistic young people. Barnardo’s NI recommends suitable investment is provided to enable the development of support groups specific to the siblings of children with autism.

• Transitions

Many disabled young people we speak to are anxious about transition and very worried about receiving little or no support services as they get older. They are concerned about the lack of information relating to available services for them after the age of 18 and strongly advocate that suitable plans are put in place to support their transition into adult services.

The Action Plan provides that integrated transition plans are developed for children with autism under the responsibility of the CYPSP Regional Transitions sub group, and this is very welcome. However, we are
unclear why the CYPSP is not more visible throughout the Action Plan particularly in respect of early intervention and family support.

"I don’t know what I’m going to do when I’m eighteen in a few weeks, I feel worried and anxious. I have only been told I’m moving to adult service, that’s it” (Young person)

• Employment and employability

This section is disappointing in its general lack of detail. The number and diversity of young people on the autistic spectrum needs to be identified and a sustainable pathway to employment developed that is also linked to transition. Young people with autism would also like more volunteering opportunities and work experience to assist them in learning vital skills for the future. It is essential clear links are made in this section of the Action Plan to the Pathways to Success NI NEET Strategy.

"Volunteering has helped me learn how to work as part of a team and become more independent. I know what my job is and I just go and do it. It’s letting me see what it’s like in the working world. I really enjoy it” (Young person)

"Volunteering made me more confident and helped me realise that I could go out there and do things” (Young person)

"I need support to experience what it would be like to work” (Young person)

• Accessing justice

This is the strongest section in the Action Plan, both strategically and operationally, and is to be commended. Barnardo’s NI again recommends inclusion of a new forensic health service and greater emphasis on early intervention to reduce the number of young people with autism entering the juvenile justice system.
• **Being part of the community**

This section should include the CYPSP as a body with responsibility given the Partnership’s direct influence on locality planning and family support hubs, which tend to be voluntary and community sector led. We would suggest that DE and SureStarts are also responsible and that clear links are made to the extended and community school networks.

Barnardo’s NI further recommends that Local Councils should be included in this section, especially considering the vital role they play in ensuring young people with autism have opportunities to participate in local leisure services and community activities. Young people would also welcome easily accessible information about what is on offer for them,

“...there should be a database of services available in each area so we know where and what we could do” (Young person)

• **Participation and active citizenship**

In principle Barnardo’s NI warmly welcomes the key action to involve people with autism in the design, development and review of policy. In our experience however this can only be translated into a workable model through appropriate facilitation and funding in order to be effective. Often these types of initiatives can be parent rather than child-led and we strongly recommend that the voice of the child is paramount.

Moving forward in respect of this Action it will be important to learn from best practice. The Barnardo’s NI Disabled Children & Young Peoples Participation Project (DCYPPP)\(^1\), for example, facilitates the views of children and young people with a range of disabilities, aged 5 to 25 years, in influencing activities, and also their involvement in high level strategic Children’s Services Planning.

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\(^1\) The project is based in the Southern Health and Social Care Trust Area.
Summary of key recommendations:

- The Autism Strategy and Action Plan should more clearly link in with the wider strategic framework.
- Clear, measurable targets relative to the key actions in each section must be developed.
- All Government Departments should be clearly invested in developing and implementing the Autism Strategy and Action Plan.
- Non-statutory representation should also be included on the Autism Strategy Implementation Group.
- Additional investment must be secured to ensure successful implementation; especially regarding the provision of early intervention and family support services pre and post diagnosis.
- Invest more in early intervention training for education and health professionals, especially at GP level.
- Invest in the development of support groups specific to the siblings of children with autism.
- Improve intra and inter agency working in respect of the management of comorbidity.
- Include education as a distinct strategic priority given its critical role in developing better outcomes for children with autism.
- Provide clarification about what constitutes appropriate education provision; and evaluate provision in mainstream schools.
- Prioritise the progression of initiatives to capture relevant data and enhance autism research to ensure the development and delivery of appropriate autism services.
- Provide clarification about where the Middletown Centre for Autism sits within both the Strategy and the broader autism network.
- Consider the impact of welfare reform changes as the Autism Strategy is being taken forward.
- Review and evaluate the ‘Six Steps of Autism Care’ departmental pathway.
- Link in the development of a new Regional Forensic Health Service with the proposed referral pathway between criminal justice agencies and HSC Trusts.
- Ensure that joint working arrangements between HSC Trust autism services and Education autism intervention and advisory services are in place early and consistently applied across HSC Trusts.
- Include Local Councils, DE and SureStarts in relation to being part of the community, and make clear links to the extended and community school networks.
- Develop a workable model based on good practice to ensure that participation and active citizenship for children with autism is meaningful, effective and child-led.
**Further information:**

For further information about any of the issues discussed in this paper, or to find out more about Barnardo’s NI Disabled Children & Young Peoples Participation Project (DCYPPP), please contact:

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