

## **Barnardo's NI**

### **Submission to the Department of Health Autism Strategy 2023-28: Pre-Consultation**

Barnardo's NI is the largest children's charity in Northern Ireland. Every year we work with more than 18,000 children, young people and families across more than 45 different services and programmes. We are a leading provider of schools-based support, reaching more than 32,000 children in schools across the UK and Ireland through our NI-managed social and emotional literacy programmes.

We deliver a wide range of services, from providing family support and early intervention, to working directly with children and families who have experienced adversity and need our support. Our goal is to achieve better outcomes for more children. To achieve this, we work with partners to build stronger families, safer childhoods and positive futures.

Barnardo's NI welcomes the opportunity to input into the pre-consultation on the Autism Strategy. Our comments are informed by our experience of supporting children and young people with autism and their families.

Barnardo's NI Home Links is a short break support service for disabled children and young people including children with a learning disability, autism and challenging behaviour. Children are given the opportunity to have fun, share experiences and socialise outside of their home life while giving their parents or carers a brief break from caring. The service matches children to carers and workers based on a number of factors, including the child's needs and the carer/worker's experience.

Our Willowgrove service provides a range of regular short-term breaks and support services to children and young people aged 5-17 years old with a learning disability, including children with autism. The children and young people experience enjoyable and stimulating breaks alongside their peers at the purpose-built bungalow and in the wider community. The facilities at the bungalow include a state-of-the-art sensory room and fully accessible sensory playground.

Our response provides an overview of the key issues that Barnardo's NI believes this new strategy should address, as well as pointing to examples of good practice currently being delivered to children and young people with autism and their families.

## **1. General comments**

- 1.1. Barnardo's NI welcomes this initial consultation in the development of a longer-term Autism Strategy for Northern Ireland. There are considerable challenges that the Department must address in the commissioning and delivery of autism services, however these challenges are not insurmountable. An open, collaborative approach to service design and delivery, alongside a well-funded action plan to implement this strategy will be key to addressing these challenges and making sure that children and young people with autism have the opportunity to live happy and healthy lives.
- 1.2. As the Interim Strategy (2021-22) highlights, rising demand and long waiting lists are the core issues for autism services. Funding and resources have not kept pace with the rising need, and as a result, support has become very thin on the ground. The issues within the current system are complex and deeply embedded. A clear example of the challenges that the sector faces is highlighted by our own experience with Forward Steps.
- 1.3. Our specialist autism service, Forward Steps, closed in May 2020 after supporting children, young people and families for 20 years. Forward Steps provided a specialised support programme for pre-school children diagnosed with autism and their parents or carers. This service was highly regarded by service users and commissioners alike and provided support to over 1,000 children with autism and their families through improving communication, behaviour, sleep or anxiety issues. The Forward Steps building was designed, and purpose built for children with autism, with playrooms planned to support the needs of children at any point on the autism spectrum.
- 1.4. Forward Steps was an evidence-based service, achieving significant positive outcomes for children and families, yet the service still had to close due to lack of funding. Achieving sustainability for a specialist autism service in the climate of fractured commissioning and funding of autism services across NI was not possible, even for an experienced service provider like Barnardo's NI with a highly trained, expert staff team. Parents and children have lost a valuable support service and the wider autism network has lost the expertise of this staff team.

## **2. The post-diagnosis vacuum**

- 2.1. While the 2013-2020 Strategy had a number of shortcomings, a clear success was awareness raising of autism and signposting for children and parents to receive a diagnosis. This is evidenced in the sharp increase in autism diagnoses over a relatively short period of time. While this success is an important one, it unfortunately led to some of the more significant challenges regarding the implementation of the Strategy.
- 2.2. The landscape of need and provision of autism services has changed drastically since the initial strategy published in 2013. When the initial strategy was published, it was estimated that approximately 1 in 100 children had autism; since then that estimate has been revised up to 3 in 100 children. This represents a threefold increase in demand for support, services and funding required and expertise needed. The resource and funding allocated to the 2013 Strategy did not build in enough flexibility to meet the demand that would accompany increased diagnosis.
- 2.3. Before the development of the 2013-2020 Autism Strategy, a comprehensive review was undertaken to understand what people with autism, including children and their families, needed and how to best support them. A new autism strategy must begin with this fundamental work to understand the current level of need and the gaps in the system. This work must highlight the successes of the previous strategy and critically review those aspects that were not fit for purpose.
- 2.4. From our experience supporting children and young people with autism, one of the biggest challenges facing families is a post-diagnosis vacuum. Many parents and carers believe that a diagnosis is the key to unlocking access to services, and they feel disappointed and let-down when they realise this is not the reality. Once a child or young person receives a diagnosis, they often join a long waiting list in order to access services or additional support.
- 2.5. Parents or carers whose child has just been diagnosed with autism are often offered group training sessions that fail to answer the questions they have or equip them with the skills and knowledge they need to best support their child. Barnardo's NI believes that parents should be offered training to the same standard as the basic training offered to professionals. The return on investment for the Department would be lifelong as parents and carers will continue supporting their child throughout their life.

### **3. Gaps in current autism service provision**

- 3.1. Often, children with autism are separated from their peers when it comes to accessing universal services, with autism-specific services having even longer waiting lists. Barnardo's NI recommends that a foundation level of autism training is provided to all professionals working in universal services, including, but not limited to, education (from nursery to higher education), early years and helplines. Not only will this ensure that children who have autism, but no official diagnosis, receive a good standard of care and support, but it will begin the cultural shift of mainstreaming autism support and moving towards a society that meets the needs of all children and families.
- 3.2. Mental health provision is recognised in the interim strategy as a key priority; however, Child and Adolescent Mental Health Services (CAMHS) is only referenced in response to the 'Still Waiting' report, with no reference to the specific mental health support needs of children and young people with autism. In Northern Ireland, it is currently very difficult for children with autism to access mental health support that meets their needs, and where provision is available, it is inaccessible to most children and young people given the location of the service. Our services have reported that some families travel long distances to access Modified Cognitive Behavioural Therapy designed for people with autism, which they must pay for privately. For many families, both the cost and additional travel can act as a barrier to accessing this support.
- 3.3. Additionally, there is no reference to in-patient mental health facilities for children and young people with autism. We ask the Department to provide further information on what is currently available, and whether that provision is suitable and sufficient.

### **4. Commissioning autism services**

- 4.1. There is a need for a review of the commissioning environment for autism services. Currently, money is divided into a number of small pots within the Trust areas. This has resulted in differential support depending on a child's postcode. This approach is contrary to the Children's Services Co-operation Act (NI) 2015 which requires agencies to work together to achieve the best outcomes for children, including pooling of funds.
- 4.2. The specialist skills to provide tailored support to people with autism are concentrated in the voluntary sector. However, funding of voluntary sector services has been piecemeal, and as a result,

specialist services, like Forward Steps, have had to close due to funding challenges. Consequently, generic services have been tasked to fill the gap, and children and families that need specialist support are finding that their needs cannot be met; this is particularly concerning given the ongoing impact of a global pandemic and restricted access to support networks.

- 4.3. Barnardo's NI recommends that the Department of Health develops a centralised commissioning approach, with Trusts accountable to the Department of Health for spend on autism services and support. Additionally, access to services should be standardised throughout Northern Ireland, with good practice models developed in one Trust, being funded and replicated in the other Trusts. Access to services should not be a postcode lottery.
- 4.4. Furthermore, while the vast majority of our families prefer to go down the route of official diagnosis, this is not always the case. In a select few instances, we have found that when some parents feel supported from an early stage, they later decide that they do not need to get an official diagnosis. Where parents and carers feel they can best meet the needs of their child with the support they have already received, and do not need further involvement of statutory services, this can also be in the best interests of the child.
- 4.5. We would encourage the Department of Health to work more closely with the Department of Education in responding to the needs of children with autism, including pre-diagnosis and early stage support. Although the Department of Education was involved in the development of the 2013-2020 strategy, implementation was driven by the Department of Health. Barnardo's NI would encourage both Departments to work alongside each other to make the system less complex and support more accessible to children and families.
- 4.6. Additionally, there is a role to play for other Executive Departments, such as Department for Communities in relation to suitable housing, and the Department for the Economy in relation to further and higher education, and employment opportunities. All departments must work together to ensure that children and young people with autism have the same opportunity to grow up and lead full and fulfilling lives.

## **5. Pathway of support**

- 5.1. One of the biggest challenges facing children with autism and their families is knowing what support is available to them at the different stages in their journey and as they move through life. Barnardo's NI recommends that as the Department develops this new Autism Strategy, it seeks to lay out a clear pathway of support that is designed for children and families.
- 5.2. The pathway should outline the support available at the different ages and stages in a person's autism journey from childhood to adulthood, and how services and support can be accessed. These pathways need to be family-centred and address the support needs of parents and carers as an integral part of a child's life. Additionally, the design and delivery of these pathways must be in a clear, accessible format that is suitable for children with autism and their parents and carers.
- 5.3. Barnardo's NI believes that a clear, straight-forward pathway will not only help set expectations about what is ahead, but also make sure that children and families are able to access the right support at the right time. Barnardo's NI would be keen to work with the Department on the development of this pathway, alongside a group of young people from our Disabled Children and Young People's Participation Project (DCYPPP).

## **6. Engagement and collaboration with autistic people**

- 6.1. We welcome the publication of the easy-read consultation document for this consultation process. This is a small action that can make a big difference to engaging directly with children and families with a lived experience of autism.
- 6.2. In addition to providing an easy-read version of consultation documents, we would also encourage the Department to carry out direct, ongoing engagement with key stakeholder groups, including children with autism and their families. This will allow the Department to hear directly from those most impacted, to understand their needs and what support would best meet those needs.
- 6.3. When designing services for children and young people with autism and their parents or carers, we would recommend that the Department examines undertaking a collaborative or co-design process. By involving people with lived experience in the design and delivery of service provision, we will move closer to providing services that genuinely meet the needs of the people they serve.

## **7. Examples of good practice**

- 7.1. Barnardo's NI has been supporting children with autism and their families for many decades, and as a result, we have identified and developed a number of evidence-based interventions and models of good practice that we would like to highlight to the Department in the development of the new strategy.
- 7.2. A version of the Incredible Years Programme<sup>1</sup> has been developed, specifically aimed at supporting parents of children with autism – The Incredible Years Autism Spectrum and Language Delay Programme. This programme consists of 12 two-hour sessions, designed for parents of children aged 2-5 years old who have been diagnosed with ASD or language delay. The programme covers eight topics including: positive relationships, language development and school readiness, social coaching to promote friendship skills, emotion coaching to promote emotional literacy, pretend play promoting empathy and social skills, and promoting self-regulation skills.
- 7.3. A pilot evaluation of the Incredible Years Autism Spectrum and Language Delay Programme has shown positive results indicating significant reductions in overall parental stress following participation in the programme. The importance of heightened levels of parental stress cannot be underestimated in terms of the impact on parental wellbeing, functioning and ability to manage the needs of the child and family, as well as child outcomes.
- 7.4. Barnardo's NI's Forward Steps was innovative in being the first service in Northern Ireland to develop autism sleep programmes for children, and anxiety workshops to help parents support their older children. However, it was the Forward Steps Parenting Programme, developed over 20 years, that captured the essence of the Forward Steps work. This programme was based on the firm belief that each child should be able to actively take part in family and community life. The aim of the programme was to:
  - Enable parents/carers to understand how autism was affecting their child's development,
  - Give parents/carers the skills to communicate effectively with their child,
  - Provide parents/carers with information on local services for children with autism and their families.

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<sup>1</sup> The Incredible Years is a series of evidence-based programs for parents, children, and teachers, supported by over 30 years of research: <https://incredibleyears.com/about/>

7.5. The Parenting Programme ran for eight weeks, of which six weeks were spent at our purpose-built premises, including parent theory and information training, assessment of each child's needs and practical live training for parents with their children. Onsite training was followed up each week at home and in the community addressing issues parents were seeking help with e.g., toileting, bedtime, going on the bus, shopping, going to the hairdressers. Throughout the programme, staff linked with early years services, schools and other professionals to ensure a consistent approach with the family and to act as advocates for parents. The Forward Steps team continues to raise awareness of this programme, including sharing the programme with other teams working with children with autism and their families.

## **Conclusion**

Barnardo's NI welcomes the Department of Health's initial engagement on the Autism Strategy 2023-28. While the 2013 strategy succeeded in raising awareness of autism, it was not equipped to meet the demand that followed an increase in diagnosis. We hope that this strategy will get straight to the heart of the critical challenges facing the services that support children and young people with autism and their families.

In order to successfully address these challenges, the Department must invest the necessary resources and funding, work closely with both statutory and voluntary sector partners, and ensure that autism support is standardised throughout Northern Ireland. We welcome the Department's approach to open engagement and consultation, and we encourage further direct engagement and collaboration with people with autism.

For further information, please contact:

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