

Barnardo's NI

Response to the Interim Autism Strategy, 2021-2022

January 2021

Barnardo's NI is the largest children's charity in Northern Ireland. We work with approximately 12,000 children, young people and families annually across more than 40 different services and programmes. We deliver a wide range of services across Northern Ireland, from providing family support and early intervention, to working directly with children and families who have experienced adversity and need our support.

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

Our specialist autism service, Forward Steps, closed in May 2020 after supporting children, young people and families for 20 years. Forward Steps provided evidence based programmes to assist parents and carers with understanding their child's autism, how to support their child's development and their child's specific needs. This service 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 set-up to provide the best support to children with autism, with playrooms designed to support the needs of children at any point on the autism spectrum.

Barnardo's NI also delivers short break support for children and young people with disabilities, including autism. Through these services, children have 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. Home Links matches children to carers and workers based on the child's needs, while Willowgrove is a purpose-built bungalow which houses facilities such as a sensory room and sensory playground.

Our response provides general comments on the current landscape of autism services and support in Northern Ireland, and outlines our concern that an Interim Autism Strategy will not be fit for purpose to tackle these issues. The second section provides an overview of the starting point for a new long-term autism strategy, which is where we believe the Department should concentrate its time and resources.

1. General comments

- 1.1. While Barnardo's NI welcomes the aspirations of the Interim Autism Strategy, we are concerned that the strategic outcomes outlined in the document are not realistic and the key priorities of the interim strategy are not achievable in a two-year period.
- 1.2. Barnardo's NI is concerned that time and resource will be diverted to pursuing a short-term strategy when the need for a more in-depth review of autism support in Northern Ireland is urgently needed. This interim strategy will not address any of the fundamental issues and burdens that families currently face.
- 1.3. As the interim strategy highlights, rising demand and long waiting lists are the core issues for 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; challenges that cannot be resolved by a light-touch, short-term strategy. A clear example of the challenges that the sector faces is highlighted by our own experience with Forward Steps.
- 1.4. 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. Forward Steps was evidence based, achieving significant positive outcomes for children and families, yet the service still had to close in May 2020. 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.
- 1.5. While recognising the shortcomings of the current strategy, Barnardo's NI recommends that the Department extends the Autism Strategy 2013-2020 for the interim period. This time could be used to commission an in-depth, external review of the Autism Strategy 2013-2020 to understand the lessons learned and review the data collected.
- 1.6. The landscape of need and provision of autism services has changed drastically since 2013. When the 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.

2. Developing a long-term autism strategy

- 2.1. Barnardo's NI would welcome and support the Department in the development of a new, long-term autism strategy. Below we will provide an overview of some of the key issues and challenges currently facing the autism sector. This is not an exhaustive list of issues, however addressing these challenges must be the starting point for any long-term strategy.
- 2.2. 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.
- 2.3. 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.
- 2.4. 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 current environment of a global pandemic and restricted access to support networks.
- 2.5. 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.
- 2.6. 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. 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.

- 2.7. Finally, we welcome the commitment and intention in the Interim Autism Strategy to co-production; this must be followed through with real, meaningful action. Going forward, as a first step, we recommend that an easy-read consultation document is published when any consultation process is launched. This is a small action that the Department can take to begin meaningful engagement with children and families with a lived experience of autism.
- 2.8. 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.

Conclusion

Barnardo's NI welcomes the opportunity to respond to this consultation. We recognise the intentions of the Department to improve autism support in Northern Ireland, however we believe this will not be achieved through a two-year interim strategy. We strongly encourage the Department to consider extending the 2013-2020 Autism Strategy and to use the time and resources to fully and meaningfully develop a long-term strategy that will improve the lives of children and families with autism. We hope our comments are constructive and useful, and we would be happy to further discuss any of the above comments with the Department.

For further information, please contact:

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