Autism Strategy 2023-28 consultation response

March 2023

About Carers NI

1. Carers NI is Northern Ireland's membership charity for unpaid carers. We work to represent and support the over 220,000 people in Northern Ireland who provide unpaid care for ill, older or disabled family members or friends – fighting for increased recognition and support for all carers and to ensure they have a voice in policymaking.

Introduction

2. Carers NI welcomes the opportunity to contribute to this consultation on a future Autism Strategy for 2023-2028. Our response to the consultation has been informed by detailed engagement with unpaid carers of people with autism spectrum disorder in Northern Ireland – including a focus group session, one-to-one feedback exercises and other consultative activities.
3. Where appropriate, this is supplemented with wider research and evidence. Throughout this document there are stories and quotations from unpaid carers who support people with autism in Northern Ireland.
4. Most of this consultation response will focus on those policy areas that carers identified as priorities in our engagement with them. It must be recognised, however, that unpaid carers are impacted directly and indirectly by the entirety of this strategy and the themes within it.

Key points on the Autism Strategy consultation from unpaid carers

- Carers are disappointed that the consultation document fails to fully recognise and give due regard to the role of unpaid caring in supporting people with autism. While it is right that many of the questions/follow up questions in the consultation focus on the needs of those diagnosed with autism, greater attention could have been paid to the experiences of all of those involved in autism services; including the unpaid carers who, in many cases, play key communication, advocacy and other roles to ensure people with autism can access the services and supports they need.
- Carers are essential partners in care and are often the first source of support and empowerment for those with autism when they are interacting with public services. This should be recognised in core strategic policy documents like the Autism Strategy.
- Many public services, including health, social care and education, are struggling to meet the support needs of people with autism. In particular, there are significant challenges in the spheres of early intervention, assessment and community support. Unpaid carers are often at the forefront of filling gaps in these services and supports, across every stage of the person's life cycle. This is pushing many carers to breaking point, with some struggling to continue providing the levels of complex care required for lengthy periods of time. It is therefore essential that a future strategy take account of the realities facing many families and carers and take steps to improve outcomes for them.
- Grater collaborative working between Executive Departments, Health and Social Care Trust and other agencies/public services would greatly improve the experiences and lives of unpaid carers of people with autism.

Consultation themes

Waiting lists for autism assessments/adult autism services

5. Unpaid carers share the frustrations with assessment waiting times that have been long expressed by families living with autism across Northern Ireland. They told us that waiting times for assessment and diagnosis are lengthy and can vary significantly between Health Trusts – not only impacting negatively on the person with autism, but also preventing carers from getting the support they need in their caring roles.

6. Of particular concern, some carers we engaged with explained that they hadn't been able to undertake a Carers Assessment – a crucial gateway to accessing support – because the person they are caring for was still awaiting a diagnosis. This is unacceptable and we believe that the cared-for person being on an assessment waiting list should be sufficient for their carer to be offered a Carers Assessment – a formal diagnosis should not be necessary.

   "My child is waiting formal diagnosis, which is a 2.5yr waiting list. I can't do anything [in relation to getting a Carers Assessment] until he has a confirmed diagnosis."

   "Our life is on hold until my child completes his autism assessments. We cannot access support, we cannot get financial support, we can't do anything until the assessment is completed and we have a diagnosis. But that is years away at the minute."

Emotional wellbeing and mental health

7. Carers told us that they do not feel that their emotional or mental health is recognised or prioritised when caring for someone with autism. Many don't feel listened to or supported by public services, and this – combined with the pressure they are under in their caring role – is reflected in nearly 40% of carers of people with autism describing their mental health as bad or very bad in our last State of Caring survey. [1]

8. While this situation is driven by a range of factors, the lack of access to breaks and respite (see below), gaps in the social care system and challenges accessing care packages and wider support is putting carers of those with autism under considerable pressure and contributing to mental burn out and exhaustion. Again, this is reflected in our research:

   - Nearly 40% of carers of people with autism told our State of Caring survey that not having the time to prioritise their physical and mental health was among the aspects of their wellbeing that they worried about the most.
   - Nearly 70% identified more support to look after their own health and wellbeing as among their top needs as a carer.

9. This evidence illustrates that, while the Autism Strategy – as a standalone policy document – has a role to play in better supporting the mental health of carers, it cannot do so comprehensively in isolation. The wider reform of the adult social care system will be critical to ensuring carers of those with autism have access to the services and supports they need to maintain their own health and wellbeing while caring.

Short breaks and respite

10. As the consultation document recognises, Covid-19 has, and continues to have, a disrupting impact on access to short breaks, respite and day services – which are yet to return to full pre-pandemic capacity across Northern Ireland as a whole.

11. This situation is a source of deep frustration and pressure on unpaid carers, with 56% of carers of people with autism telling Carers NI's last State of Caring survey that more breaks

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[1] Carers NI (2022). State of Caring 2022: A snapshot of unpaid caring in Northern Ireland.

or time off was among their top needs as a carer; and nearly 40% saying that being unable to take a break was among the three aspects of their wellbeing that they worried about the most. Overall, just 30% of carers of people with autism said that they had had a break from caring in the previous 12 months.

12. Carers are clear that access to regular and reliable breaks from caring is key to improving their health, wellbeing and quality of life. For too many carers, the provision of short breaks or respite – if it is available at all – is delivered on an ad hoc and limited basis; with no certainty as to when provision will become available and little notice given in advance.

    "I have had short breaks for an hour max. I really night an overnight break or longer, but there are no services available to me for this."

    "Really need respite care for the child, but it is impossible to get these days."

    "Less than an hour a week break is not enough."

    "I can never have a break. I can't access any suitable respite at all."

Transitions

13. The unpaid carers we engaged with highlighted a number of core themes related to transitions. In a broad sense, they had had mixed experiences regarding the planning and implementation of transitions across health, education, housing, employment and more for the person they care for. These transitions can be incredibly challenging and this underlines the need for proper consideration and implementation of the cross-departmental components of the Autism Strategy.

14. Secondly, a recurring theme expressed by carers centred around the services and supports for those they care for when they, the carer, are no longer around. Northern Ireland's aging population means that many older people are caring for family members and friends with autism, and there is a palpable fear among many such carers about the options available when they are no longer able to care or when they eventually pass away. This does not just concern health, social and personal care, but other things like housing arrangements as well.

15. To help address these challenges, carers advocated for a *whole life planning approach* – one that assesses the needs of people with autism across the life cycle and in a holistic way, and therefore softens, or ultimately removes, the jagged edges so often associated with transitions in the spheres referenced above.

Housing

16. Housing is an important issue for carers of people with autism. They told us that the process of finding suitable accommodation in the community is a daunting and lengthy process, both for cohabitation with the person they care for, and when the person they care for becomes an adult and wants to live independently. While it is to be welcomed that the Autism Strategy consultation includes a housing element, detailed proposals and funding arrangements will be required to address the long-term housing support and provision needs of people with autism and their unpaid carers. This must include supported living arrangements and Supporting People funding.

17. Carers also highlighted the long delays in accessing Disabled Facilities Grants (DFG), and expressed concern about the limited range of options available under the DFG system to improve housing for families living with autism. For example, it was suggested that grants should be available to deliver adaptions and improvements orientated around the sensory needs of people with autism (such as sensory rooms) – not just physical needs (like ramps or stair lifts etc.).

18. More widely, there is an urgent need to give greater consideration to housing needs when undertaking Carers Assessments. In our State of Caring survey, more than one in three carers of people with autism said that the suitability of their housing for continuing their caring role was not properly considered in their Carers Assessment or in the support they received afterwards.

Additional comments

Carers as expert partners in care

19. Unpaid carers of people with autism are experts by experience. They have a great wealth of insight into the needs of the person they care for, and how public services can meet those needs, but too often they aren't acknowledged as expert partners in care.
20. Carers expressed deep frustration about being excluded, or insufficiently consulted, when decisions are being made about the services and supports provided to the person with autism that they care for. Doing so dismisses a core pillar in that person's life and one of the central sources of expertise on their needs. As we have advocated previously, Carers NI believes this can be addressed with a new statutory duty on Health and Social Care bodies to treat unpaid carers as strategic partners in care and involve them in care planning and decision-making.

    "My opinion as a carer didn't carry any weight. They [HSC professionals] didn't want to share any information or discuss anything further. I felt left out."

Financial hardship and poverty

21. A common issue raised by many of the carers we engaged with for this consultation response was financial hardship and poverty. In our State of Caring survey, over 40% of carers of people with autism said they were struggling to make ends meet, with 80% saying the cost of living crisis was negatively impacting their physical and/or mental health.
22. This is an important theme to consider in a future Autism Strategy, especially given the focus on employment in the consultation document. Providing unpaid care leaves many people without the time to go to work – less than half of carers of someone with autism told our State of Caring survey that they were in employment – and the support they receive from the social security system is often entirely inadequate. It is critical that the Autism Strategy includes commitments to work on a cross-departmental basis to deliver better financial support to carers and the wider help they need to enter and stay in the labour market.

    "It's a spiralling monthly situation, where each month we need more debts to cover living costs. Every month we get further into our overdraft or use more of our credit card. [After the autism diagnosis] I was unable to continue to work and this has meant losing a wage at the same time as prices are increasing."

    "I had to give up my job after 24 years as my son was diagnosed with autism and needed me at home."

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