

**British Association of Social Workers response to the Department of Health consultation on the Autism Strategy 2023 – 2028**

Thank you for the opportunity to respond to the Department of Health consultation on how to develop the action plan for the next Autism Strategy 2023-2028.

The British Association of Social Workers Northern Ireland (BASW NI) is part of the British Association of Social Workers (BASW), the largest professional body for social workers in the UK. BASW has 21,000 members employed in frontline, management, academic and research positions in all care settings.

Social workers support autistic children and adults and their carers. Services for autistic children and adults are provided in a wide range of locations including but not limited to specialist autism teams, learning disability services, family and childcare services, child and adolescent mental health services, adult mental health teams, day care, and residential settings.

Whatever the configuration, care for autistic people is achieved through multi-agency approaches, featuring different professionals from both the statutory and third sector. Within this context, social workers are relied upon because of their whole systems understanding of peoples' needs and organisation of services.

As per our BASW Practice Guide '*Social Work with Autistic People*' the foundational values of social work with autistic children and adults are recognising, appreciating, and promoting the values of neurodiversity. As a 'spectrum' of conditions, autism impacts uniquely on each individual. This may be visualised as a continuum, at one end, individuals need minimal support whilst others at the other end of the continuum, may need high levels of care. Social work with autistic children and adults is underpinned by principles of personalisation. This means holding the individual at the centre of practice, working with them to identify their unique abilities and challenges, and working alongside them to achieve their self identified needs.

## **Waiting lists for autism assessment**

BASW NI is acutely aware that waiting times for autism assessment and support in children and adult services are at an all-time high across Northern Ireland with thousands of patients on an unacceptably long list. Demand for diagnostic and intervention services across the Health and Social Care Trusts continues to increase at pace. The commissioned systems in their current form are not able to meet current or anticipated future demands. Recurrent financial investment to meet recurrent demand is needed in addition to funding to address the gap in capacity and demand that has been growing over the past number of years and that was further exacerbated by COVID-19. Without investment, waiting lists will continue to get longer for diagnostics and intervention.

Many adults and carers of children are choosing to have an assessment carried out privately due to waiting times for diagnostics in the Health and Social Care Trusts. This comes at a high financial cost of over one thousand pounds, a cost that is prohibitive to many, creating further inequality and a two-tier system in our service provision. As private providers often provide a diagnostic assessment only and not post diagnostic support or autism specific intervention, those children and adults where appropriate, have to be then referred into their respective Trusts for intervention. Intervention also has lengthy waiting lists and this delay between diagnostics and intervention is challenging for children at a time of uncertainty for them and adults adjusting to a diagnosis later in life.

The Autism Strategy notes the importance of early support and intervention. Timely access to both diagnostic and autism specific intervention services should be a top priority for the Strategy. The challenges that a delay of support for children, their families and carers is significant on their emotional wellbeing. The action plan for the Strategy should be cognisant of *The Children and Young People's Emotional Health and Wellbeing in Education Framework (2021)* which aims to strengthen the integration of services for children requiring support, including autism. It is evident that families continue to struggle to navigate their way across paediatric services and

are often on waiting lists for more than just autism services. Support can therefore feel disjointed across health and education systems.

Measurement of outcomes for autism services for both adults and children are currently based on waiting list data, this data collection does not capture or help us understand the outcomes for autistic children and adults in relation to their goals. A comprehensive piece of work needs to be done to explore outcomes in a meaningful way to help strategically plan long term for future services and inform action plans across government departments and the health and social care sector which are aligned to the Programme for Government.

### **Adult Autism Services**

Funding in adult autism services falls significantly short compared to demand for its diagnostic and intervention support. Implementation of the strategy in adult services needs to be through a person-centred approach. Autistic Spectrum Disorder is a spectrum with each person having different talents and needs, abilities and problems. The Strategy should be needs and not diagnosis led. This is especially important for service users presenting with multiple conditions. On this basis there is no generic plan that will meet the needs of every person. This requires investment in person centred plans that fit the needs of each individual, and in services that have the flexibility to accommodate these plans to ensure delivery of a personalised service. These plans are best met through a multi-disciplinary framework including social work input.

### **Emotional Wellbeing and Mental Health**

Supporting the emotional wellbeing and mental health of children and adults with mental health needs who are autistic from a social work perspective requires a focus on needs and strengths, and not diagnosis alone. The Strategy should be focusing on preventative work on this basis. In children's services families want a service that is based on needs not determined by diagnosis.

In adult services regular health assessments can ensure the identification of co-occurring health conditions and prevention of worsening mental health of autistic adults. Including sensory needs and triggers of crises in all assessments can reduce behaviours whose management challenge professionals and carers, and co-production of de-escalating plans of crises can prevent involvement of coercive psychiatric treatments.

### **Short Breaks and Respite Services**

Respite care for the caregivers of autistic children is one of the most important types of support that are identified to social workers. The framework for children's disability services that seeks to restore and further extend short breaks provision needs to deliver for children with disabilities, and their carers, who were so badly impacted by COVID-19 across Northern Ireland.

Many carers of autistic children and adults face significant daily challenges in supporting the autistic person, with carers often living according to the autistic person's needs, and consequently prioritising their needs over their own, to the detriment of their own health and wellbeing.

More emphasis on supporting those who care for autistic adults is required as they are often indispensable to those they care for. Many carers feel taken for granted by the statutory bodies that would otherwise have to shoulder the burdens and costs of care and alternative accommodation options for autistic adults.

Carers of autistic children and autistic adults have, when there is an assessed need, access to self-directed support and direct payments and use this as a form of help and respite. Social workers often report that trying to find personal assistants or support workers is extremely challenging for carers due to the low numbers of such skilled workers in the community and the fact that an hourly rate of pay does not appeal to many people. It can be an unrelenting and recurrent cycle to secure this support. Without this support for the autistic person, the emotional wellbeing of the carer can quickly deteriorate.

In order to prevent burnout carers need formal supports, their immediate community needs education and awareness, while health and social care professionals including social workers need the knowledge and understanding of autism to support them effectively.

## **Transitions**

Autistic children and adults experience transitions every day, this could be 'minor' occurrences such as moving between activities, or significant life events such as transitioning to adulthood, moving homes, hospital admissions, or change of social worker. Every transition experience is unique to that individual; thus, support and intervention must be person-centred and strengths-based. Whatever the transition may be, the need for planning is essential.

For an autistic young person entering adulthood, they may experience changes in their care plans and a potential reduction of services. Whether an autistic child was known to Child and Adolescent Mental Health Services or Family and Childcare Services can also impact on transition planning. BASW NI is aware that social workers in this area of practice are advocating for change and improvement, given that in many cases, the experience of transition between services is inadequate, at individual and systems levels.

One issue of concern to both autistic people and carers, and which many feel needs more attention, is what happens as they get older. A significant transition faced by many people with autism as they get older comes when their parent carers are no longer able to support them at home. Many autistic people continue to live at home with carers well into adulthood, and parent carers are therefore likely to be nearing and entering old age while still providing substantial care to people with often very significant needs. Social workers are very aware that that potential for sudden breakdowns in caring arrangements is high, and too many autistic people may find themselves hurriedly placed in settings that are inappropriate.

Older autistic adults are less likely to access physical healthcare on their own and often enter the healthcare system at the point of severe health decline. This can result in expensive nursing home placements or hospitalisations. They are also less likely to ask for adaptations to their property or domiciliary care.

There has understandably been a focus on child to adult transition in the Autism Strategy. Transition from children's to adult services which is relevant across many of the selected themes in the Autism Strategy—including education, skills training and employment—requires ongoing focus. However, support for autistic adults facing transition in the life span should not be overlooked. Autistic adults face some key transitions as they age, such as retirement and bereavements, and it is important that people receive appropriate support. Financial investment in adult services is not highlighted in the strategy, but establishing better access to services for adults with autism will require substantial resources.

### **Educational Environment**

Greater transparency in the educational system, better communication with carers, and a clearer focus on outcomes for children with special education needs are messages that are often relayed by carers to social workers. In an unprecedentedly challenging financial climate for the Education Authority, the financial support available for special educational needs and disabilities has reduced while the number of special educational needs pupils has risen. Proposed budget cuts of one hundred million pounds are particularly concerning and are affecting the day to day running of the schools, transport and outcomes for special educational needs of children and young people.

In considering how children and young people are supported in special educational settings it is vital to remember that all behaviour is communication. This is especially relevant when considering the needs of children and young people who are non-verbal.

BASW NI is concerned that training currently provided to teachers and support staff may not focus sufficiently on de-escalation training and low arousal approaches, leading to unnecessary use of restraint and seclusion. The result is that what should be used as a last resort, in crisis situations, is being used overly-frequently, without regulation, recording or reporting to parents and families. These concerns from parents and families continue to be reported to us.

BASW NI considers it regrettable that the lack of a Northern Ireland Executive has prevented the planned introduction of statutory guidance on the use of restrictive and support practices for educational settings. The guidance proposed by the Department of Education is intended to include a requirement for staff in educational settings to have access to appropriate training and de-escalation techniques to prevent behaviours of concern reaching a crisis that requires physical intervention. The introduction of this guidance should be taken forward as a priority on the formation of a Northern Ireland Executive.

Physical space matters to children and adults on the spectrum and space can be limited in schools and day centre facilities. Spatial organisation of therapeutic spaces for children and adults who are sensitive to their physical surroundings is important and continuing commitment by the Department of Education is needed to adapt and improve buildings for those who require these spaces.

Autistic adults are ten times more likely to drop out of third level education than their neurotypical peers. University can be a very anxious time due to the number of transitions involved, including moving out of home, often for the first time, learning in a less structured environment, and much noisier and busier environment than school. Sometimes it is only after dropping out of university that an autism diagnosis is sought following mental ill health.

What must be at the core for educational environments, whether that is school, further education colleges, or universities, is improved understanding and acceptance of autism and the ability to respond to individual needs with support and reasonable adjustments.

## **Employment**

Reducing the barriers to employment is very important to autistic adults.

Approximately only 22% of autistic adults are in any kind of employment. Detailed actions are clearly required to improve employers' understanding of autism, and more support both for job seekers and employees. Traditional approaches of access to employment such as interview can be particularly challenging for individuals and is dependent on employers' knowledge of the core features of autism to enable improved accessibility in recruitment processes.

While we acknowledge that not all autistic people can work, most who can want to. Employment can provide financial independence, self-confidence, purposeful activity and self-esteem. Additionally, it is an activity which enables a pathway to independence and self-reliance. More options for flexible options as gateways to employment are required.

## **Housing and Community**

We need a range of housing and independent living accommodation which is appropriate to meet specific needs. There are a vast range of housing issues and housing needs for both children and adults on the spectrum. Viable options in Northern Ireland are lacking for autistic people across the life span.

Many children and adults who have autism, learning disabilities and associated mental health needs are admitted to secure settings because of the lack of the right housing and care. There are issues with funding shortages and long delays to discharge into adequate support and homes, as evidenced by the situation facing inpatients at Muckamore Abbey Hospital.

Preventative, community-based services should be in place to avoid this from happening. Community disability social workers are being let down by a lack of community infrastructure and future planning at the highest levels. They share the frustration of the children and adults they are supporting and see first-hand how they are being let down by a failing system.



The in-patient hospital environment is not therapeutic for autistic people and is actively damaging, which in turn leads to preventable use of restraint and ongoing detention. It is a false economy not to have the right homes with the right support in place to help people live the dignified and happy lives that they deserve. Housing goes hand in hand with social inclusion. Housing, whether it is in a supported living environment or independent living, is regarded as a prerequisite for many autistic adults to be able to achieve progress in other areas in their life and have the opportunity for independent living. Too many autistic adults continue to live at home with their parents when they don't want to due to a lack of options and support. It is not just that in many areas people cannot find the accommodation they need, the stresses of not being properly housed or being unsuitably housed often trigger mental health problems. Having flexible housing support options is key, including having a range of support options which can be adapted to fit the needs of the adult with autism including floating domiciliary support.

Social and community support for autistic children and their families is of vital importance too. Social workers often act as brokers to navigate systems in order to link families to needed resources and services. They often have an educational role with carers in relation to what services and support are available and how they can access them. Social workers also facilitate interactions between the children and families, and the various service providers and support groups. Community focused social options, where social contact is available in an autism friendly context, outside of the family network, is often lacking for adults. In the absence of self-generated social connectedness, a level of formal provision is required which enables access to fulfilling structured activity. Accessing and enjoying hobbies, meeting new people—including meeting likeminded people who have similar interests—and having a social life aside from their family life, is crucial for the social well-being of autistic adults.

BASW NI looks forward to continued engagement with the Department on these issues. If you would like any further information or to arrange a meeting to discuss this response, please contact Noeleen Higgins, Registered Social Worker and BASW NI Professional Officer, [noeleen.higgins@basw.co.uk](mailto:noeleen.higgins@basw.co.uk) / 07435289912.