



Comhairle Ceantair
Lár Uladh
Mid Ulster
District Council

24 February 2023

Autism Strategy Delivery Team

Department of Health

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Ref: Consultation Response on Autism Strategy 2023-2028

To whom it may concern:

Mid Ulster District Council would like to take this opportunity to put forward its views in relation to the Department of Health's Consultation on the development of the Autism Strategy 2023-2028.

Individual feedback will be provided on each of the following areas identified in the consultation:

1. Waiting Lists for Autism Assessment
2. Adult Autism Services
3. Emotional Wellbeing and Mental Health
4. Short Breaks and Respite Services
5. Transitions

6. Educational Environment and Further and Higher Education
7. Careers and Employment
8. Housing
9. Our Community

1. Waiting Lists for Autism Assessment

The benefits of early diagnosis and early intervention to support individuals with Autism is well documented. Currently there are entirely unacceptable waiting-lists time for diagnosis (reported as up to 3years). Consequently a significant number of individuals and their families are suffering from a lack of support and intervention which is having impacts across all of the other 9 areas being examined as part of this consultation process.

There is also great disparity between Trust areas in both waiting-lists times and the type of support each Trust provides to a person diagnosed with Autism. This has created a situation of post code lottery healthcare, creating a disparity between people being enabled and supported to live a full life and find coping strategies for areas of their life that they may find challenging. Therefore it is clear that the current waiting times create a barrier to accessing support services and the ability of a person with Autism to achieve their full potential. Not only are they being denied early intervention but in some instances a diagnosis doesn't lead to appropriate access to long term appropriate support interventions.

Current methods of diagnosis assessments also vary throughout Trust areas. The use of remote assessment methods may be useful in some cases to increase accessibility. However, given the social and emotional aspects of Autism, the limitations of this method have to be recognised. The individual themselves or their parents/carers should be consulted with regarding whether or not this method is appropriate for them. Given the length of time someone may have waited to be assessed it is imperative that the correct assessment method for them is utilised.

The underrepresentation of female diagnosis is also something that should be addressed by the Department. It is widely recognised that women and girls' masking of autism symptoms can lead to a delay in their consideration for diagnosis. Over generations this had led to autism being more frequently diagnosed in boys and men. The diagnosis process should therefore address the disparity between behaviours displayed by all genders.

2. Adult Autism Services

As highlighted in other areas of this response, the waiting times for assessment and diagnosis vary greatly across the Trust areas. Again, the support and follow-up services provided post-diagnosis can also differ greatly. This can lead to adults slipping through the net and in some cases failing to ever receive a diagnosis and the associated support that they require. In some cases, adults who would benefit from an assessment are then treated for other associated health conditions such as anxiety and depression. These conditions can stem from an inability to manage their primary condition which has not been diagnosed. This lack of diagnosis can negatively impact on all aspects of adult life, such as training and employment, relationships and caring responsibilities.

3. Emotional Health and Wellbeing

In terms of providing emotional health and wellbeing support for people with Autism, it is clear that in the Mid Ulster District Council area, as well as many other areas, the Community and Voluntary sector provide a lot of the limited support available. These groups are overwhelmed and in some cases have families on waiting lists. These groups were often originally set up to serve just their local locality, but because of the dearth of funded support the groups now support families from across the District. This situation worsened during the pandemic and it was evident that a vacuum for emotional health and wellbeing had been created and that the Community and Voluntary sector were filling that void. However, these same groups struggle for

funding to maintain the services which individuals with Autism and their families have come to depend upon.

The provision of peer support and targeted activities, as well as a supportive listening ear has proven invaluable to families in the Mid Ulster District. As such, the Council would like to take this opportunity to commend all the volunteers who work tirelessly within the District to provide such effective support to families who require it. However, the Council would also urge the Department to appropriately fund this local provision of emotional health and wellbeing for people with Autism and their carers.

4. Short Breaks and Respite

The feedback received by Mid Ulster District Council on the provision of short breaks and respite care is that, within this large rural district, this provision is severely lacking. Unfortunately, it can be the case that the respite offered is such a long distance from the family home that the time and effort taken to travel to the respite location outweighs the overall aims and benefit of the respite provision. Mid Ulster District would recommend that respite is tailored to the need of the family who are in receipt of it and that it meets the aim of providing a rest for care givers instead of causing additional stress just to gain access to it.

Feedback has also been received by Mid Ulster District Council that the Direct Payments system can be cumbersome for families to manage and implement. This is further exasperated by the lack of appropriately trained care staff. The fact that trained staff are offered a meagre hourly rate of pay for the important and essential work that they carry out makes it even more difficult to access appropriate support. Mechanisms to ease this issue, such as a register to match up appropriately trained carers to families who require support, would be greatly welcomed.

5. Transitions

The characteristics of Autism mean that individuals do not like change and may not cope well with it. During times of transition, individuals with Autism can require additional support in order to ensure that they can employ appropriate coping strategies. Autism Support Groups from the District have reported that this practical support is in extremely short supply. This can lead all types of transitions going unsupported and unmanaged or managed and implemented by people without the appropriate knowledge and skills set. Therefore, during transition is one of the times when individuals will require practical support and where it seems to be currently most lacking is via a lack of access to social work support. As well as a lack of social work support, the current pressures within the Social Care sector also directly impacts on how successful transitions period for individuals with Autism can be. The Council would recommend that by addressing diagnosis waiting times and employing appropriately trained staff to manage transition periods for people with Autism the outcomes for individuals could be much improved.

6. Educational Environment

The challenges SEN students face in Northern Ireland to access the appropriate help and support is well documented. However, it is clear that one of the main issues is accessing support because of the lack of diagnosis. Therefore the length of time children and young people are having to wait for an Autism diagnosis is directly impacting on their educational attainment. Diagnosis and support often comes too late to be effective in a child's education because the opportunity for early intervention has passed. Mid Ulster District Council would recommend that there is more joined up working with Early Years services so that parents and carers are supported to seek diagnosis at the earliest possible juncture and that appropriate support can be identified and implemented prior to and during the process of diagnosis. However, this is only a useful strategy if the current diagnosis backlog is resolved.

Remaining in education (and employment) can also be difficult due to some of the characteristics of autism, such as difficulties in developing relationships, inflexibility in thinking, a need for routine, behaviour that can be seen as challenging and a tendency

to be focused on single subject. As such, post-primary schools should employ more targeted support for individuals with Autism in order to ensure that they are encouraged to remain in education. Therefore, appropriate and tailored support needs to be implemented within education settings in order for children and young people to remain in the system and enable them to fulfil their full potential.

7. Careers and Employment

Similarly, to post-primary education, careers and education can be difficult to maintain and progress within, for individuals with Autism. This can also be largely attributed to attitudes and a lack of awareness. This lack of awareness can lead to employers not considering the characteristics of Autism and the needs and preferences of individuals. As such, Mid Ulster District Council is of the opinion that career options for individuals with Autism could be vastly enhanced by increasing employers' awareness and ultimately acceptance of the condition. Current recruitment processes and practices can act as a significant barrier to paid employment for individuals with Autism.

8. Housing

While there is an overall lack of suitable housing stock in Northern Ireland and this shortage impacts particularly negatively on people with a disability because of a concentrated lack of supported and accessible housing. This lack of provision presents a significant barrier for vulnerable people who have Autism but who also have the ability to develop and maintain independence. In some cases, the alternative to assisted living is long-term hospital care, the negative ramifications of this was recently highlighted in Mencap's 'Homes not Hospitals' campaign. It contrasted the huge benefits on patient outcomes of independent living with the outcomes for individuals who are not afforded independent living, but instead have their lives confined and restricted within a hospital setting. Unfortunately, the reality for many individuals with Autism is that their full potential cannot be met because of the lack of assisted living provision in Northern Ireland.

9. Our Community

Mid Ulster District Council recognises and supports community efforts to provide awareness raising of Autism and support moving to acceptance of the adjustments to community provisions and service delivery to meet the needs of Autistic individuals. However, there is a lack of funding and training provision to allow the majority of community provisions to be truly inclusive via person centred approaches to reasonable adjustments and inclusivity. It is important that everyone feels part of their community via equal opportunities. As such, the Council would encourage the Department to work with and support local communities to enable them to engage with people with Autism and their families. This engagement could address local need/demand and tailor community activities and provision to meet requirements so that effective and tangible inclusive efforts are evident in all communities.

As well as feeling excluded from general events and activities in our communities, individuals with Autism can also face barriers to accessing general care requirements in our communities. This is most evident in relation to accessing GP services and Social Services contact. GP services can be difficult for individuals with Autism to access because they currently do not consider of the characteristics of Autism. There is also a lack of awareness of the importance of addressing the needs and preferences of individuals in order to meet their medical requirements. This is a barrier that can be addressed by tailoring services and making GP appointments more accessible.

In relation to accessing Social Services contact, individuals with Autism can go for long lengths of time without being able to get in contact with the appropriate social worker. This leads to delays in accessing referrals for required support.

Overall, Mid Ulster District Council has found from consulting with local Autism Support Groups that there is evidence of individuals with Autism being unable to fulfil their potential because of delays in diagnosis which leads to a lack of referral for support. This is further compounded by a lack of joined up working between Departments once a diagnosis has been obtained. Finally there is a general lack of tailored provision for

individuals with Autism and this can frequently stem from the professional not being provided with appropriate levels of knowledge and training.

It is the opinion of Mid Ulster District Council that health provision needs to change to meet the needs of the individuals with Autism. Often these changes aren't significant or costly but without appropriate provision, barriers are created for individuals with Autism and unfortunately the barrier can become insurmountable leading to negative outcomes and unfulfilled potential. The Department should place appropriate staffing and resources to ensure that individuals with Autism should be supported as much as possible to live healthy and fulfilled lives.

Yours sincerely

Córa Corry

Chair of Mid Ulster District Council