

CARERS IN HERTFORDSHIRE C4A CO-PRODUCTION SESSION SUMMARY

Two sessions took place in one in August and one in September 2020. Carers were provided with materials to read prior to the sessions which detailed findings of phase one of the Review of The Autism Diagnostic Pathway - Adults.

They were then asked to consider the following questions:

DO THE FINDINGS FROM PHASE ONE OF THE REVIEW REFLECT YOUR EXPERIENCE? IS THERE ANYTHING ELSE YOU WOULD LIKE TO ADD?

ASSESSMENT

It was felt that there was much more awareness needed of the diversity of the autistic community. Professionals need to understand autism and masking in girls and women in order that this group be identified earlier, and barriers for assessment removed.

SUPPORT

Carers identified that support was needed in key areas for autistic adults:

Mental Health, Everyday living, (including self-care, transport and organization,) to help with difficulties connected with executive functioning and sensory issues. Also support in social communication and developing social networks. Generally, carers felt that a lack of support often led to a crisis and mental health issues becoming more entrenched. At times this would lead to substance abuse, in an attempt to self-medicate and the lack of support and understanding in the outside world prompted challenging behaviour. Carers felt their ASD family members were more vulnerable to abuse by others and sometimes leading to contact with the police, who often fail to identify and understand an individual with ASD. In terms of the future for their autistic family members carers highlighted the lack of information and advice relating to the availability of supported accommodation and housing, as one of their most pressing concerns. Carers felt that their young adults would benefit from some form of mentoring, to encourage them to access appropriate services and overcome barriers associated with ASD in order to lead a fulfilling life.

SUPPORT FOR CARERS

The point that came across most strongly was the need for carers to be able to have a break from being the sole support for the family member with autism. Often difficulties arose due to the invisible nature of the disability and led to others having high expectations of their family member which caused problems. Carers also felt that there was a need for initial support for them at the point of diagnosis, to enable them to understand and come to terms with what this would mean and to be able to explain this to family members and professionals.

The lack of support services available for adults with autism means that family carers were often the only source of emotional, social and financial support long into adulthood, even when the family member was living independently. In addition, the lack of early intervention support services meant that often adults had to be at a crisis point to receive any sort of service and that often the services provided were not fit for purpose in terms of being autism friendly. From the carers point of view services were not readily available and when they were provided, appropriate help had to be 'fought for' in one case involving their MP. The constant battling and trying to negotiate complex pathways between different agencies often left carers exhausted and overwhelmed with no energy for their own needs. In addition, Carers of adults with autism and a mild learning difficulty expressed the view, they were often confused, they felt there was not a clear fit for their adults in terms of services and that they often fell between two stools.

The cost of the lack of support and no respite from caring impacts carers health, wellbeing and their ability to support themselves financially or in some cases enjoy any sort of 'retirement'. Carers expressed their fears about who would take over their role in the event of their death.

WHAT TYPE OF SUPPORT WOULD HELP YOU OVERCOME THESE CHALLENGES?

Carers were very clear they would like their cared for adults to be able to easily access appropriate and timely services, so that they could 'have their own life'.

There were lots of ideas expressed about the type and range of services that might help, priorities identified were;

- Time to themselves and the choice not to care or to stop caring when the time came
- Housing: information and advice about options
- Mentor and buddying, peer support for ASD Adults
- An Autism Hub, with an advice line that provides a sign posting service
- Carers have repeatedly said they valued having a named specialist social worker, when Adult Social Care had the Asperger's Service. Having someone who knew their family and provided consistency for their cared for person and them as carers. Avoiding them having to retell their story again and again.
- Autism Mental Health Specialists, to provide the right support at the right time.
- Support Groups for Autistic Adults, allowing them to connect with others of a similar age or with similar issues
- An online forum for those who prefer not to engage face to face and text support services
- Courses both face to face and online for ASD adults, helping to them understand their differences and to overcome barriers. E.g. Social Skills

training, negotiating reasonable adjustments, coping with sensory overload and using public transport, managing money, work and autism.

- Courses for carers: E.g. dealing with issues relating to self-care for adults with autism, supporting a family member with autism, dealing with challenging behaviour and keeping yourself as a carer safe, talking to autistic adults about relationships.
- Access to support and counselling to support carers emotional well-being.