Autistica Action Briefing:
Post-Diagnostic Support for Adults

AUTISTICA

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Autistica is the UK's autism research charity. This briefing summarises the most important scientific findings about post-diagnostic support for autistic adults. It was developed in collaboration with leading researchers and autistic people with experience of adult diagnosis as an insight into the latest evidence.

We strongly urge the Department of Health and Social Care, NHS policy-makers, commissioners, services and public research funders to act on this information. Chances are being missed to tackle autistic health inequalities. Supporting autistic adults when they receive a diagnosis and throughout their lives is crucial for improving those outcomes. Services and public policy need to see post-diagnostic support as their opportunity to make a difference.   **www.autistica.org.uk/AutismStrategy**

> "Support services are practically non-existent for adults. Our outcomes are abysmal. The attitude that 'if we got by this long, we can continue to get by' is horrifying. We have already lost so much." [1]

What we know

> "We are given the diagnosis and then left to sink or swim with no support and no assistance." [1]

- **A lack of support after diagnosis is the norm rather than the exception,** particularly for autistic adults without a learning disability.[2] Despite large demand for post-diagnostic support[1] and a significant impact on outcomes,[3] the options available for autistic adults are often limited or non-existent.[1,2,3,4,5,6]

- **Services are often not commissioned or funded to support people after diagnosis.** Despite growing clinical consensus that follow-up support should be offered to maintain good health and optimise quality of life, many diagnostic teams are not resourced to implement this. Some can only offer group-based services which are inaccessible to some autistic people, whilst others cannot offer any support at all.[7,8]

- While autism is not a mental health condition, **mental health conditions affect the majority of autistic people.**[9,10,11,12] There is an opportunity to introduce low-level support which could reduce the need for crisis or inpatient services.[1,13,14,15]

- **Autistic people have poorer health outcomes**[16] and are more likely to experience a range of conditions.[17] Following up effectively after diagnosis creates opportunities to identify and overcome health inequalities, a key priority in the NHS Long Term Plan.[18]

- **Autistic people report a lower quality of life**[19] **and face exceptionally high rates of unemployment**[20,21] **and social isolation,**[22,23] both of which also impact health outcomes.[24,25] Support beyond diagnosis could enable autistic people to access opportunities to play a more active role in their communities and the economy.[26]

What we need to find out

> "No follow-up support was offered. They told me I was too old and that I did not need it... All I got was two website addresses on a piece of paper." [1]

Too little research has focused on the ideal ways to support autistic people as adults.[4,27] Receiving an autism diagnosis is a key opportunity to help autistic adults access the support they need. For this to be effective, research needs to consider:

- Which services and professionals are currently involved in supporting autistic adults immediately after diagnosis in the UK? How effective are existing post-diagnostic support models in improving quality of life for autistic adults?

- What methods of delivering psycho-educational support are effective at helping autistic adults come to terms with what their diagnosis means and maximising their quality of life?

- How can diagnostic teams most effectively co-ordinate support for autistic adults after diagnosis between referrals to mainstream services or specialist post-diagnostic services?

- To what extent is longer-term, low-level support effective in improving outcomes for autistic adults? How can effective "step-on, step-off" support, available as and when needed by autistic adults, be made sustainable?

- Are peer support programmes effective for improving post-diagnostic outcomes (e.g. mental and physical health, wellbeing, understanding of autism and autonomy) for autistic people?[28] How can we optimise peer support programmes for personalised goals?

What we should do now

"Feeling shaken and vulnerable, I went to my GP to see what help or support might be available in adapting to life with my diagnosis, and the answer was 'None'." [1]

- Autistic people require varying levels of support at different points in their lives, for example during transition to adulthood, commencing employment, retirement and bereavement. However, there are currently few contact points within the NHS for autistic adults after diagnosis, aside from inpatient settings and services for people with learning disabilities.

NHS England should consider supporting Sustainability and Transformation Partnerships and Integrated Care Systems to pilot models of ongoing low-level support for autistic adults and collect data to evaluate the effectiveness and sustainability of different approaches.

- Post-diagnostic support has a vital role to play in tackling poor health outcomes among autistic adults, and there is increasing evidence about how to do it more effectively.[7,8] The Long Term Plan made tackling autistic health inequalities an NHS clinical priority but how diagnosis and ongoing support for adults will be improved has not yet been specified.[18,29]

The NHS Long Term Plan workstream on autism should prioritise work to identify optimal diagnostic and post-diagnostic pathways for autistic adults. This should be considered alongside other initiatives in the Long Term Plan, like the introduction of health checks for autistic people.

- The 2014 Adult Autism Strategy[30] set out that making *"person-centred local health, care and support services"* available for autistic people was one of the *"priority challenges for action"*.[31] This is still not the case in most areas. The importance of person-centred care was recently highlighted by the National Autistic Taskforce.[32]

The Department of Health and Social Care should ensure that its new Strategy[33] includes a specific focus on supporting autistic adults after diagnosis.

- Changes to the Mental Health Services Data Set last April mean that more reliable data will become available about autistic adults and their interactions with NHS services.[34,35] This data could help provide valuable insights into the healthcare services autistic adults use beyond diagnosis.

NHS Digital, NHS England and the National Institute for Health Research should meet with the Department of Health's autism data group to commission an analysis of the services autistic adults use after they have been diagnosed, using the MHSDS and other public sector datasets.

- Autistic people frequently report the need for low-level preventative support,[1] and such approaches have found success in other fields such as mental health.[14]

The Department of Health and Social Care, NHS England, and public, private and third sector research funders need to collaborate to facilitate research around low-level, cost-effective interventions to support autistic people and their families beyond diagnosis.

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