

A public health approach to reducing health inequalities among adults with autism

People with autism make up around 1% of adults living in the community across the UK.¹ Autism is a neurodevelopmental disorder which manifests from early childhood, with persistent deficits in social communication and social interaction across multiple contexts, along with restricted, repetitive patterns of behaviour, interests, or activities. The current guidance enables diagnosis of autism from level one to three based on the level of support needed to overcome the challenges posed by restrictive behaviours and social communication deficits.²

The health needs of adults with autism is of public health interest because this vulnerable population are socially disadvantaged and often 'hidden' from existing health and social care services.¹ Autism is more prevalent in males, those without educational qualifications, and those living in social housing.¹ People with autism with or without an intellectual disability (ID) are at higher risk of multimorbidity in the physical and mental health domains.³ Around 30% of adults with autism have comorbid ID, physical, and mental health conditions.⁴ Additionally, a recent study using Scotland's 2011 census data, found that adults with autism ($n = 6649$) can also experience sensory impairments, such as deafness/hearing loss (14.1%, $n = 939$) and blindness/sight loss (12.1%, $n = 807$), which can cause additional communication problems.⁴

While those with comorbid ID are more susceptible to physical health issues,⁵ those without ID are at higher risk of mental health problems, including higher than normal suicide rates.⁶ Adults with autism without ID die 12 years earlier, with suicide being the greatest cause of premature mortality.⁷ Therefore, this vulnerable population have significantly higher premature mortality rates when compared to the general population. Addressing the complex and disparate health needs of adults with autism requires innovative population based strategies to inform, enable, and empower the target group and its stakeholders.

ACCESSING APPROPRIATE AND TIMELY HEALTH CARE

Importantly, many of these adverse health outcomes are avoidable and can be addressed through appropriate levels of preventive health care, support, and lifestyle interventions. Tailoring the levels of severity

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detailed in the *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5)⁵ can be used to inform future interventions. It is important to address factors contributing to these adverse health outcomes in adults with autism. Evidence from childhood studies suggests that these include diet and/or nutritional problems, social impairment, sedentary behaviours, emotional problems, and avoidance behaviours.^{8,9} As has been proposed in the *NHS Long Term Plan*,¹⁰ adults with autism may benefit from accessing an Annual Health Check (AHC), which are routinely offered to adults with a learning disability.^{11,12} People with ID share many of the primary health and social concerns adults with autism have. Despite challenges in delivery, the concept and mechanism of AHCs are considered an effective approach to identifying and managing a wide range of health conditions.¹³ Unfortunately, adults with autism, unless they have a comorbid ID, are not routinely offered an AHC because NHS bodies are not incentivised in the same way as supporting adults with ID.¹⁴

Additionally, adults with autism experience a range of barriers to appropriate and timely health care and support. These include issues that are intrinsic to the nature of autism (sensory impairment, for example, being unable to experience pain; communication difficulties; health literacy; anxiety; avoidance behaviours or lack of routine; inertia; neglect; and social isolation),¹⁵ but also insufficient reasonable adjustments that take into account the patient's specific needs.¹⁵

Organisationally, healthcare barriers include an inflexible approach to care settings, lack of autism leadership or champions in institutions, lack of clinical understanding of complexity of co-occurring physical and mental health issues, and diagnostic overshadowing.¹⁴ Corporate health care is divided into rigid specialties from commissioning and resource perspectives, leading to gaps in the system. Thus, complex patients with multimorbidity are highly prone to fall through these gaps. These barriers contribute to 74% of adults with autism reporting that they experience difficulties

in accessing health care, and 88% felt that health professionals failed to understand their health needs.¹³ Reduced access to timely and appropriate health care contributes to the inequalities experienced by adults with autism. This represents a significant burden on society and health and social care services, costing the UK economy £32 billion per annum due to poor physical and/or mental health, and loss of earnings.¹⁴

REDUCING HEALTH INEQUALITIES

The Westminster Commission on Autism¹³ made an overwhelming case for preventative health care through AHC for adults with autism. This is supported by national legislation (such as, the Autism Act 2009), national policy, and guidance, such as those from the National Institute for Health and Care Excellence (NICE),¹⁶ which support the need to identify and manage people with autism's unmet health needs. The *NHS Long Term Plan* recently committed to the introduction of a specific AHC for people with autism, which will be extended more widely if successful.¹¹ In addition, there is ongoing consultation on the need and type of autism training in all statutory public sectors.

While this is encouraging, some of the above barriers may continue to persist and influence the levels of uptake of preventative health care and support. These barriers make it challenging to support those with autism in a general practice, especially due to the wide spectrum of presentation and range of abilities.¹⁷ Consequently, GPs would benefit from endorsing the Autism Patient Charter (a framework developed by RCGP and Autism Alliance to make primary care practices autism friendly. It provides five broad areas — staff awareness, communication, reasonable adjustments, environment, and behaviour management — for practices to consider in relation to supporting people with autism) and implementing the RCGP Autistic Spectrum disorder toolkit.¹⁸ Such a toolkit could inform a range of issues including support in the delivery of reasonable adjustments, access to formal autism training, and overcoming issues such as diagnosis and clarity around

referral pathways.¹⁹

Additionally, the development of an anonymous national primary care autism register¹⁴ can help overcome the 'hidden' nature of autism. Adopting an autism register can help target those who may benefit most from healthcare interventions, especially if the DSM-5 suggested levels of autism model is used. However, some adults with autism may not welcome this approach because of potential negative stigma in areas such as employment.

PUBLIC HEALTH APPROACHES

Annual Health Checks along with 'autism friendly' practices with increased awareness among professionals, the provision of reasonable adjustments, and clear information, can help meet the health needs of adults with autism holistically.¹⁰ In addition, public health and health promotion teams in local authorities, social care, current autism charities, and health bodies, are well placed for developing alternative forms of health care and support (complementary to AHCs), which could potentially help overcome some of the obstacles that are intrinsic to autism. For example, the utilisation of existing budgets could help the delivery of support outside of traditional NHS settings, which may include exploring social prescribing opportunities.

A co-created 'health interview' to help adults with autism overcome emotional, communication, and sensory impairments, may reduce barriers seen in formal NHS settings. To be effective, these should be combined with the availability of AHCs. Developing, harnessing, and the testing of new technologies in health and social care, may further alleviate high levels of health needs among this population; for example, delivering a virtual consultation at the person's home using video-based web tools.

Finally, prior research has focused on childhood populations with a paucity of research on the health needs of adults with autism and a lack of direct health assessments, particularly in more rural environments. Further research is needed to understand the health needs of this vulnerable population across the life course to guide the development of future interventions to meet the health needs of adults with autism.

CONCLUSION

To maximise the potential benefits of AHCs for adults with autism, it is necessary to develop more holistic and collaborative ways of working with other bodies, such as adult social care and public health. This may be achieved by co-creating public health

approaches, such as social prescribing or additional 'health interviews', which are offered outside of NHS settings, to help overcome some of the barriers to accessing timely and appropriate health care. This may help alleviate some of the individual and healthcare pressures. Additionally, working collaboratively with wider stakeholders will help engage with the 'hidden majority' of adults with autism (those who remain unknown to existing services), which will improve the effectiveness of AHCs.

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Funding

This article was supported by Cornwall Public Health function. No external funding was obtained.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

Rohit Shankar has received institutional and research support, and personal fees from LivaNova, Union Chimique Belge (UCB), Eisai, Veriton Pharma, Bial, and Desitin, outside of the submitted work. All other authors have declared no competing interests.

DOI: <https://doi.org/10.3399/bjgp19X706133>

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