Working with Autistic Young People

A research-informed guide for Practitioners in Education, Youth Work, Youth Justice and Social Care.

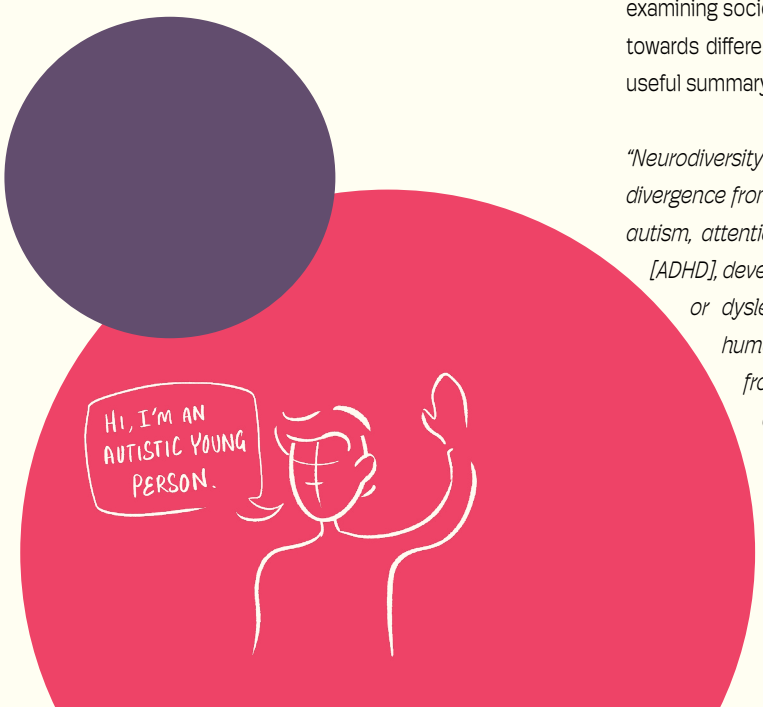
This resource has been designed for the purposes of bringing recent research on autistic young people to a wider range of youth practitioners in an accessible format. In this booklet you will find guidance on avoiding labelling and preferred terminology, an explanation of neurodiversity and four research case studies from Education, Youth Work, Youth Justice and Social Care. Each case study closes with recommendations for practitioners and signposting of further resources.

NTU Nottingham Trent University

Avoiding labelling & preferred terminology

There is debate about how autism should be described. Some terms commonly used can be considered ableist because they are negative, and deficit based. Examples include special interests, challenging behaviour, symptoms, and descriptions of autism being something which requires treatment or a cure. Autism may also be perceived as a dichotomy of high/low functioning (Bottema-Beutel et al., 2021). Diagnostically, autism is categorised as a disorder – Autism Spectrum Disorder - in The Diagnostic and Statistical Manual of Mental Disorders (DSM-V; American Psychiatric Association, 2013). As such, autism discourse has emerged from the medical model of disability. However, conceptualisations of autism evolved as the neurodiversity paradigm emerged.

The language debate extends to whether person-first (person with autism) or identity-first (autistic person) language should be used. A large-scale study found that there are differences within the UK autism community as to which language is preferred and why (Kenny et al., 2016). When discussing autism, identity-first language was preferred by autistic adults, family members/friends and parents. By contrast, person-first language was preferred by professionals. Autistic adults' preference for identity-first language was because of how they perceive autism as part of their identity that cannot be separated from them. Terms such as 'autism spectrum' and 'high-/low-functioning' were rejected because it either trivialises or devalues the experience of autistic individuals. A gold infinity symbol is preferred by the autistic community, as it represents their infinite possibilities of traits, challenges and potential.



Explaining neurodiversity

Neurodiversity theory is a way of thinking about autism without using language which is medicalised and frames autistic people in need of being cured or fixed. Thinking in terms of neurodiversity shifts the focus away from any perceived deficiencies of the individual towards examining societies inherent lack of acceptance towards difference. The following quotation is a useful summary of this approach:

"Neurodiversity theory proposes that divergence from expected functioning (such as autism, attention-deficit/hyperactivity disorder [ADHD], developmental coordination disorder, or dyslexia) are natural variations of human minds, and those who diverge from the norm (neurominorities) are equally deserving of dignity, respect, and accommodation."

(Chapman and Botha, 2022)

As the quotation highlights, thinking about autism in this fashion rejects discussion of deficit in favour of difference. Such an approach aims to value the expertise of autistic people themselves whilst questioning and challenging prevailing but out-dated stereotypes (e.g., autistic people don't feel empathy). The history of autism research reveals how such stereotypes have been proliferated by non-autistic experts (Walker, 2014), and that autism itself has been largely defined with no guidance by autistic people themselves (Gillespie-Lynch et al, 2017).

Nikki Stevenson

As a previous secondary science teacher, Nikki developed an interest and passion for children with SEN (neurodiversity, traumatic life histories or circumstances) who did not attain in line with their peers. She knew these were bright, able children who faced barriers to achievement. This was vastly unfair. This culminated in the development of Insight Autism Awareness CIC which is her own company, where she has been writing and delivering training across health, social care, law, forensic services, the police, educational trusts and private businesses.

Nikki is also a post graduate researcher examining dark triad traits, neurodiversity (e.g., ADHD/autism) and empathy in the absence and presence of trauma. She works on the merits of biophilic environments for neurodivergent people and ways to streamline neurodivergent people to appropriate services and provisions and educational projects. She has lectured on Biophilic environments, Biological Psychology and guest lectured on Psychopathology. From this wealth of experience, Nikki shares her insights for working with autistic young people in educational settings.

Further Resources

https://www.teachertoolkit.co.uk/2018/01/09/reading-autism/

https://www.autism.org.uk/advice-and-guidance/topics/education

https://move2connect.com/elsa-not-for-neurodivergents/

https://kar.kent.ac.uk/62639/1/Double%20empathy%20problem.pdf

https://www.theguardian.com/profile/nikki-stevenson

Five key recommendations for Education settings in working with autistic young people

1. Sensory sensitivity is a huge barrier to attainment. Assess the young person, the environment and also any barriers to remedial intervention.

2. Psychosocial interventions must account for the differences between neurodivergent and neurotypical children–standard interventions such as the use of ELSA's may not be appropriate and may encourage and advocate masking in those with autistic traits.

3. Adopt a whole school approach after autism awareness comes autism acceptance.

4. Always allow stimming–this is the need for movements of sounds that some autistic people carry out in order to feel grounded and to ease anxiety (this may take the form of playing with fidget toys, rocking, twirling the fingers, hair or other body parts, or making repetitive sounds) do not attempt to attribute meaning to the child's facial expression nor lack of expression and allow "daydreaming" or zoning out.

5. Offer written instructions or backups for autistic students as they may struggle to retain verbal information due to the sensory environment.

Dr Alex Toft

The Under the Double Rainbow project was a collaborative piece of research that was co-produced with a group of young researchers (the Young Disabled LGBT+ Researchers Group). Alex and the group began working together in 2019 with the aim of conducting a research project together from start to finish; collaborating on all aspects of the project. They worked together in online spaces and began by defining the research area they wanted to investigate then followed by constructing everything they needed to complete the project including: research questions, data collection tools (including schedules), analysis, dissemination. The project focussed upon everyday lived experiences in relations to: identity, relationships, sensory life, perceptions, and making things better. Alex and the young researchers collected interviews and diaries from 15 participants with the overall goal of understanding how they negotiated being autistic and LGBT+ in everyday life. The findings were wide-ranging but they found there is a lot of misunderstanding about the how the two intersect and this leads to challenges for young people. As a result of this research project, Alex sets out his recommendations for Youth Work settings and LGBT+ youth projects in working with autistic young people.

For more information about their project can be found at Sociological Research Online: Toft, A., Ward, B. and Anonymous author, 2022. A young disabled LGBT+ researchers group: working collaboratively to explore the lives of young autistic LGBT+ persons.

Further Resources

Professionals may find Supported Loving's toolkit useful:

https://www.choicesupport.org.uk/about-us/what-we-do/supported-loving/supported-loving-toolkit

Toft, A., 2023. Telling Disabled and Autistic Sexuality Stories: Reflecting upon the Current Research Landscape and Possible Future Developments. Sexes, 4(1), pp.102–117.

https://move2connect.com/elsa-not-for-neurodivergents/

https://www.mdpi.com/2411-5118/4/1/10

Bertilsdotter Rosqvist, H. and Jackson-Perry, D., 2021. Not doing it properly?(Re) producing and resisting knowledge through narratives of autistic sexualities. Sexuality and disability, 39(2), pp.327–344

Botha, M., Dibb, B. and Frost, D.M., 2022. " Autism is me": an investigation of how autistic individuals make sense of autism and stigma. Disability & Society, 37(3), pp.427–453.producing and resisting knowledge through narratives of autistic sexualities. Sexuality and disability, 39(2), pp.327–344

Five key recommendations for Youth Work settings and LGBTQI youth projects in working with autistic young people

1. Listen to and value the experiences and thoughts of the autistic young people with regards to their LGBT+ identities.

2. Autistic young people may not prioritise following social conventions regarding sexuality and gender identity. Our research suggested that this says more about the rigidity of social constructions rather than autism.

3. Be mindful of the environment in which you are working. Most everyday challenges for young autistic people revolve around sensory experiences- society in general is not set-up for autistic people.

4. Young autistic LGBT+ people are not all asexual, although some of them do identify in this way. Many do desire intimate relationships, and this is just like neurotypical people.

5. Autistic relationships may be built upon things that neurotypicals do not understand or value, this does not make them deficient.

Dr Vicky Palmer

In her work as a Probation Officer and Youth Justice Practitioner, Vicky became aware that a significant number of those caught up in the Youth Justice System had either been diagnosed with ADHD or were on the Autistic Spectrum. Their over-representation seemed unjust and it was clear that few, if any of these children had received any form of help from social care agencies and instead found themselves at the mercy of the courts who would determine their future.

Youth Justice practitioners, or case managers, are professionals from a range of agencies, including social care, probation, health education and the police, who work in partnership within multi-agency Youth Offending Services. Their role is the prevention of offending in young people aged 10–18 years. Vicky's study aimed to examine Youth Justice practitioners impressions of working with young offenders with Autistic Spectrum Disorder who were subject to a range of court orders. It exposed their belief that there is an over-representation of young people with this condition being managed within the Youth Justice system. Vicky found that practitioners expressed their frustration at the absence of diagnosis for some young offenders as well as the difficulties encountered in pursuing formal diagnoses. They revealed their disappointment in the unavailability of training regarding working with young people with Autistic Spectrum Disorder and articulated their ideas concerning the nature of that training, were it made available. Finally, practitioners unveiled some scepticism over some young people's formal diagnosis; believing it to be wrongly applied. Vicky's study concluded with a deliberation of ways that practice may be improved in this area to affect a more just and humanistic approach to working with this group of young people. The following five recommendations are taken from Vicky's study and apply to Youth Justice settings.

Further Resources

Berelowitz, S. (2011). I Think I Must Have Been Born Bad: Emotional Wellbeing and Mental Health of Children and Young People in the Youth Justice System. Office of the Children's Commissioner.

Browning, A., & Caulfield, L. (2011). The prevalence and treatment of people with Asperger's Syndrome in the criminal justice system. Criminology and Criminal Justice, 11(2), 165–180.

Hayes, R. (2016). What is the relationship between Autism Spectrum Disorder and offending behaviour, if any? https://www.rcpsych.ac.uk/docs/default-source/members/divisions/london

Hughes, N. (2015). Neurodisability in the Youth Justice System: Recognising and Responding to the Criminalisation of Neurodevelopmental Impairment. The Howard League for Penal Reform.

Five key recommendations for Youth Justice settings in working with Autistic young people

1. All key practitioners in Youth Offending Teams to undertake mandatory training on working with those on the autistic spectrum.
2. All members of the Judiciary to undertake detailed training on prosecuting and defending those on the autistic spectrum.
3. All aspects of the secure estate to include a dedicated worker trained and qualified to work with those on the autistic spectrum.
4. Deliver a dedicated module on 'autism in the youth justice system' on all youth justice courses.
5. Module reading lists to contain texts related to autism and Neurodiversity.

Jenny Sanders

Jenny Sanders is a Senior Lecturer in Social Sciences, leading on student experience across the School. She also delivers teaching sessions on concepts relating to autism, social care, and the criminal justice system. Before entering academia Jenny worked in adult social care. Jenny is also completing her PhD in the Psychology Department.

When sex and autism are considered together, often it is that those individuals are either asexual or sexually deviant. Autistic individuals can want sexual relationships but may find them challenging to form and maintain. To date, research exploring this topic tends to be centred on those with learning disabilities who may or may not also be autistic. It is important to explore autism and sex exclusive of a co-occurring learning disability, not least because those without a learning disability are less likely to receive social care support. When social care support is given, it may focus on the learning disability thus not looking at the individual holistically if their autism isn't acknowledged. Importantly, social care support that is provided has little focus on sexual relationships.

Jenny's postgraduate research therefore explores the lived experiences of non-learning disabled autistic individuals' sexual education, behaviour, and relationships. The aim is to improve sexual education and support, in turn improving the sexual experiences of autistic individuals. In Study One an online survey, using the SBS-III (Sexual Behaviour Scale, version three; Hancock, 2017), had 127 responses of which 85 were autistic individuals. Compared to their neurotypical counterparts, these individuals were more worried about their sexual behaviour being misunderstood or them being taken advantage of; had more instances of speaking about sexual topics which caused others to get upset or angry; and had more difficulty understanding sexual education. The recommendations are taken from Jenny's study.

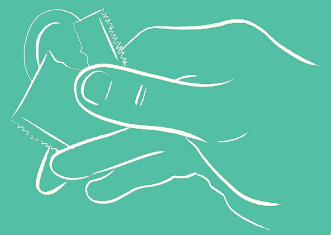
Further Resources

Supporting Autistic Adults' Intimate Lives (online resources) https://www.autlives.com/

Neurodiverse Love (podcast) https://www.neurodiverselove.com/podcastseason1

Love, partnership, or Singleton on the autism spectrum by Luke Beardon and Dean Worton

Understanding Autistic Relationships Across the Lifespan by Felicity Sedgewick and Sarah Douglas



Five key recommendations for sex and relationship education when working with autistic people

1. Content of sexual education material and training must be created with, and where possible delivered by, autistic individuals.
2. Communication differences between autistic and neurotypical individuals needs to be explored, including the double empathy problem and alexithymia.
3. Social care support and education needs to be sex positive and inclusive, acknowledging the variety of sexual orientations and sexual interests of autistic individuals.
4. An appropriate amount of time should be spent on exploring consent, including how this might look/feel/sound but also empowering autistic individuals to say no.
5. Sexual education, information and support for autistic individuals needs to be available and accessible in the community and in statutory education, not relying on a medical diagnosis or social care support for provision.

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Gillespie-Lynch K, Kapp SK, Brooks PJ, Pickens J and Schwartzman B (2017) Whose expertise is it? Evidence for autistic adults as critical autism experts. Frontiers in psychology 8: 438.

Hancock, G. (2017). Socio-sexual functioning in Autism Spectrum Disorders (Doctoral dissertation): Retrieved from https://dro.deakin.edu.au/eserv/DU:30105473/hancock-sociosexual-2017.pdf

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Walker N. (2014) Neurotypical Psychotherapists & Autistic Clients [Internet]. Neuroqueer. Available from: https://neuroqueer.com/neurotypical-psychotherapists-and-autistic-clients/

This resource has been compiled by the Youth Research group, as part of the Centre for Policy, Citizenship and Society, School of Social Sciences at Nottingham Trent University. For further information and future research possibilities, please contact Youth Research group lead

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