Do-IT Profiler
Neurodiversity Tools & Training

Rationale for Do-IT Healthcare Pathways Neurodiversity Profiler

Do-IT Solutions Ltd

Rationale:

This document provides a rationale for Do-IT Profiler Healthcare Pathways for Children, Young People and Adults.

> Do-IT Profiler designed for individuals and used in large scale organisations.

Why Implement Do-IT Neurodiversity Profiler?

01

Increasing Awareness and Expanding Demand

The awareness of neurodevelopmental conditions in both children and adults, particularly Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Conditions (ASC), has grown significantly, leading to increased demand for services across the UK.

Not everyone will have gained a diagnosis in childhood. Some adults may have been overlooked, misdiagnosed, or misunderstood in relation to a range of conditions in the past, including females who have often been missed and some misdiagnosed. In the past diagnostic traits relating to neurodivergent conditions are now recognised as having a male bias. Girls and women often can mask or camouflage their challenges and are less disruptive. This means that the challenges are seen at home by parents and often missed in school as the student seems to be coping OK (but often not at their full potential). Additionally, those navigating multiple systems and not following traditional educational routes through school and into the workplace.

02

Designing Healthcare Services

The UK government's focus is to ensure every pound spent on health is done so wisely. A combination of healthcare professional shortages and increased recognition of neurodevelopmental conditions is putting pressure on service delivery and necessitates a restructuring of service models in order to reach as many people as possible who require support.

03

Effective Identification & Prioritisation

It is crucial to effectively identify and prioritise children and adults with a range of neurodevelopmental disorders to ensure that limited resources are directed towards those with the greatest needs. deally, we need to provide help and support for all neurodevelopmental conditions including ADHD (attention deficit hyperactivity disorder), Autism Spectrum Disorder, Developmental Language Disorders, Developmental Coordination Disorder, Tic Disorders, and others.

But this needs to be across all conditions. It is also important that we do not favour some conditions more than others when we design and deliver services. They need to fit the people. If a system is inaccessible and does not meet the needs of all who need it, then we need to change the shape of delivery, not try to make people fit into one specific box or another.

04

The Numbers

A conservative estimate suggests that neurodevelopmental conditions and disorders affect 1 in 8 people. The numbers of people that are quoted can also be misleading, as they can describe individual conditions and do not account for the presence of someone with more than one condition which is in reality very common.

05

Levelling the Playing Field

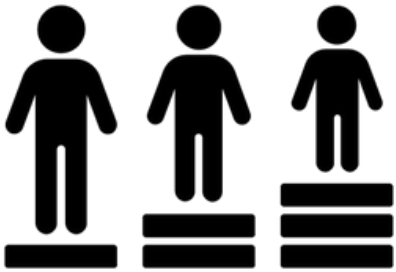
Reality check: Not everyone needs a diagnosis for support to be given. In every system there are finite resources available. What does that mean? We only have so many professionals available and so much funding to meet the needs of the whole population.

The reality is that if everyone who thought they had ADHD or Autsm was put on a waiting list it would very quickly be overloaded and just get longer and longer. This is already happening.

Recognising Inequity

Some people that have some challenges and specific conditions receive more services and support than others.

There is a variable waiting list length across the UK. Numbers are significantly higher in some parts of society, especially people who have faced adversity, those at risk of homelessness, those with care experiences, or experiencing school exclusion. In those encountering the criminal justice system the rates are at least 1 in 3 people.



The reason why there are more people in prison who are neurodivergent is not because of their neurodiversity which is often not recognised but because of the impact of adversity in their lives and neurodiversity combination having a synergistic effect i.e. 1=1=3!

Females have not always been diagnosed with neurodivergent conditions because some have been misdiagnosed with other conditions and 'female' symptoms have not always been considered.

Some people who are 'subthreshold' miss out on support. This means someone that does not meet a threshold to gain a diagnosis i.e. not quite bad enough, ending up in other services because of the impact of lack of practical support/ identification/understanding by others e.g. becoming anxious, low self-esteem, depressed, self-harming.

06

Meeting the Needs of Each Person

Categorising individuals very specifically may not always be the best way to meet their needs. Some people have complex needs that don't neatly fit into traditional diagnostic categories or services. This may mean they might end up going from one service to another or not getting the help they need at all.

It's time to shift to a different approach, one that looks at everyone as an individual. We need to consider the unique circumstances of a person in various settings, such as at home, work, with their family, in caregiver roles, and while studying. This approach is crucial for delivering quality healthcare.

There is no classical person with Autism or ADHD. Everyone is different and has a range of experiences and challenges that will mean different support needs and may also change over time. See the case studies about Jan, Alex, Tom, and Sara.

07

Path to Inclusivity

We can make a difference by:

Putting patients first: A patient-centric approach must be embedded in the design of services to provide high quality healthcare that aligns with ethical values and is more sustainable in the long run.

Training more healthcare professionals: By training more GPs, psychologists, assistant psychologists, and nurse specialists in our communities we can reach and help more people. Gaining expertise in the community will help with early diagnosis of conditions like ADHD, ensuring more people get the support they need. For those with more complex needs, it can lead to referrals to specialists like adult psychiatrists.

Expanding our services: Services will need to grow to meet the increasing demand. We understand the impact early identification and support can have on long-term outcomes.

08

Creating Practical Solutions

Providing practical tools for anyone who has specific day-to-day challenges whether they are requiring a clinical assessment or not seems to be a sensible do-no-harm approach. For example:

- Help with independent living skills such as
- organisational skills.
- Strategies for gaining and sustaining a job.
- Study skills for someone in education.
- Financial guidance such as signposting someone to the local Citizen Advice Bureau.

The tools and strategies will be different from person to person and may vary at a local level.

This is where the Do-IT Profiler system comes in and can be of real help in delivering some of these person-centred tools and strategies.

What is Do-IT Profiler?

> **Do-IT Profiler is an evidence-informed cloud-based system which is secure and robust and designed to support people who are neurodivergent in a personalised way.**

It has a track record of over a decade of use in a wide range of settings, including education and the justice setting helping to support individuals and professionals working with them.

The platform is designed to gather information in a consistent and accessible manner and provides tools to aid support and to improve communication.

Everything in one place

The system has been designed with experience and extensive feedback. The founder, Professor Amanda Kirby, is not only neurodivergent and has family members but ran a clinical centre for more than 20 years and has been undertaking research for more than 30 years in the field of neurodiversity.

This deep understanding has been the basis of developing the Do-IT system. She has written more than 100 research papers, and 10 books in the field and trained 10s of 1000s of people globally.

What we have done by designing the Do-IT Profiler system is to help pull together the relevant information about a person and present this in a format so the clinician/GP/teacher has a better overall picture and can see that all at their fingertips.

This allows them to make better and quicker informed decisions. It also helps with planning and for ongoing support as everything is in one place.

Do-IT Profiler Tools

- A contextualised, person-centered, accessible system of support tools
- A system for gathering information that enhances understanding of strengths and challenges while offering practical resources.
- Starting can be tough, especially when overwhelmed. The system offers practical strategies for areas like organisation, studying, sleep, relationships, and workplace management.
- Profiler (depending on responses) signposts to local services as well.
- Personalised guidance ensures support and strategies from Day 1, regardless of assessments or waitlists.
- The Profiler system streamlines administrative tasks, boosting efficiency for busy professionals and allowing more focus on patient care.
- The system is adaptable, translatable with content customisable to its context.

IT IS:

- A diagnostic tool or medical device.
- A tick box exercise to see if you are simply X or Y.
- A system delivering you an over simplistic IQ score that does not say who you are as a whole.
- Deciding whether you gain a diagnosis or not from specific clinical services where you live.
- Do-IT Solutions is there to enhance local service offerings. **We do not determine the local waiting list outcomes**. This is determined by the local services. Our system is there to aid the decision making processes by collating information in one place for the clinicians to see (saving time) and providing practical tools to help each person regardless of what stage the person is in gaining or diagnosis (or not needing to).

IT IS NOT:

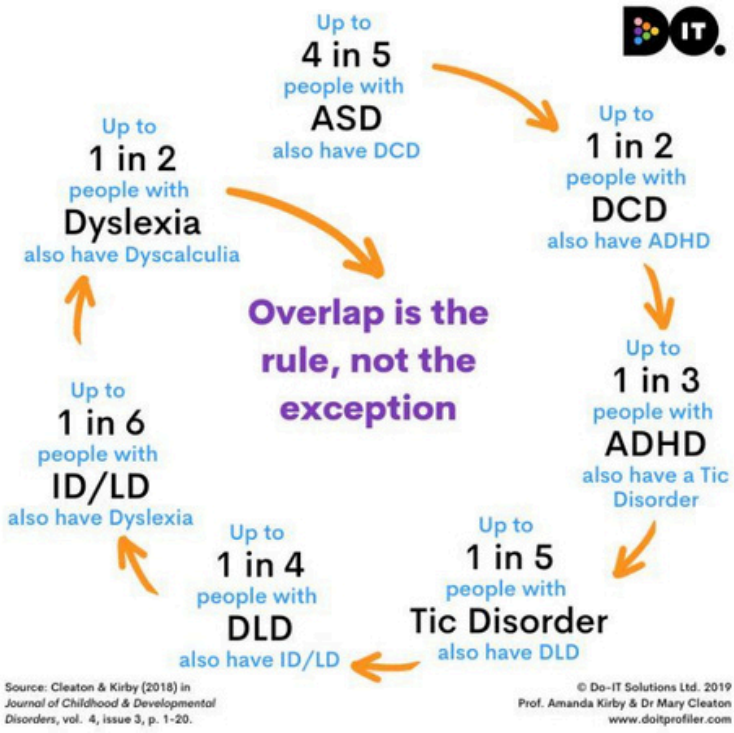
Co-occurrence

Remember: Our brains are not in neat boxes! We are messy

We can forget the extensive evidence that supports the co-occurrence or overlap of neurodevelopmental conditions. For example, about 60% of people with Autism also have DCD, (also known as Dyspraxia) and some people with ADHD will often also have Dyslexia traits as well. There is also evidence that some psychiatric conditions like anxiety, depression and bipolar disorder are more common with people with conditions such as ADHD and Autism.

When we don't consider this, it can have a cost in terms of time, and resources. Fragmentation of services can also result in repetitive processes for people having to tell their 'story' again and again and trying to navigate various services without having their overall support needs met.

Individuals can bounce between services.



Key Features

Person-Centred

- Designed to provide personalised and practical guidance to the person in the context of their lives and setting (and family).
- Profiler asks the person relevant questions relating to neurodiversity and wellbeing and also about past and present experiences for the clinician to gain a full picture of that person. This saves the person repeating information about themselves again and again and it is all collated in one place.
- Do-IT does not decide who is seen by clinical services but collates the information the person has provided all in one place reducing admin load on clinical services.

Accessible Design

- Accessible interface designed with extensive feedback from neurodivergent people.
- The system enables the person to assess their strengths and challenges relating to six areas of neurodivergent traits that commonly overlap and delivers instant practical guidance.
- The system allows the individual to complete information about important and relevant background factors that may be a factor in considering need and support. This can be done at their own pace.
- Additional tools can be added to the system depending on the clinical and local context making the information more pertinent to the end user and to clinical services e.g., entry points into services mimicking current approaches not replacing them but ensuring consistency.
- Optional tools can be included to enable ongoing support and monitoring (e.g., study skills to support someone in education; or into workplace settings/training settings).

Key Features

User Friendly Experience

- Generating instant, personalised reports and guidance.
- Accessible, voice enabled.
- Resources in multiple formats.
- Terminology can be explained to aid understanding.
- Multiple language options.
- Allowing access for those with low literacy levels or English as an Additional Language to have their needs assessed and provides them with meaningful guidance.

Labour Saving

- Reduces the need for information to be repeated by the patient and allows for instant collation.
- Information gathered provides an instant person-centred report with guidance and resources. This can be shared e.g. via email by the person if they choose to do so, and the clinical staff are able to see the information on their management dashboard,
- Reducing administrative load so more patients can be seen effectively.
- Can assist with clinical report writing pulling in relevant content into a report template.
- Easy to use and minimal need for staff training – creating a sustainable solution.
- Training content (either provided by Do-IT Profiler's or if there are local resources) on neurodevelopmental conditions can be accessed by staff if required aiding with upskilling.

The Benefits

The Profiler system holds the potential to yield short, medium, and long-term benefits as it can be adapted to create solutions tailored to local needs.
These potential gains underscore the ability of the Profiler system to not only enhance immediate efficiency but also foster sustainable improvements in healthcare processes meeting the needs of more people and helping to identify those who are in the greatest need for support.

Short Term Benefits:

Individuals

- Gaining an understanding of strengths and challenges.
- Instant personalised report.
- Practical tools and tips to help.
- Can be used to communicate needs to others.
- Person centred – every report is unique to that person.

Commissioners

- Locally designed solution understanding and meeting the needs of the local population.
- Improved efficiency of processes saving administrative and clinical time.
- Reducing the administrative load.
- Helping to maximise the local provision that is already in existence including sign posting to local voluntary sector services.
- Enhanced quality of information within neurodevelopmental systems to aid management and future planning.
- Improved communication among all stakeholders.
- Establishment of consistent pathways and processes.
- Reduced waiting times for individuals with the most pressing needs.
- Outcome measures and mapping of local needs accessible from management centre
- Accessible and transparent consent processes.

The Benefits

Clinicians

- Efficiency gains, such as time saved in document completion and collation for both the individual and the clinician.
- System can explain the processes to the patient so the clinician has more time for patient engagement.
- System provides the capability to gather information from multiple sources when necessary.
- Ability to speed up report writing by pulling information from relevant sections into the report. This can be tailored for each service.
- Free up time for more patient-clinician interaction.
- Helping to have better interdisciplinary working by reducing duplication of information.

Administrators

- Bulk upload of patients for sending out information and providing access to Profiler.
- Potential to receive an email on patient completion of Profiler so reducing the need to check if this has occurred.
- All information collated and able to gain multisource information if required.
- Person
- Delivery of information in an accessible format so that people can engage with the services equitably regardless of their access needs.
- Providing information and practical strategies from day 1 regardless if they meet the criteria for assessment.
- Providing personalised guidance across neurodevelopmental conditions and not just by diagnostic categorisation.

Medium and Long Term Benefits:

- Streamlined collation of information across and within clinical pathways.
- Maximising professionals working in the setting.
- Widening access and improving equity.
- Data and in depth understanding of local needs aid planning of services to match the needs of the community.
- Improved clinical outcomes operating a human centred model.

Useful Resources

Alexander-Passe, N. (2016), "Dyslexia: Investigating Self-Harm and Suicidal Thoughts/Attempts as a Coping Strategy", Journal of Psychology & Psychotherapy, Vol. 5 No. 6, p. 1000224.

Anderson, S.A.S., Hawes, D.J. and Snow, P.C. (2016), "Language impairments among youth offenders: A systematic review", Children and Youth Services Review, Elsevier Ltd, Vol. 65, pp. 195–203.
APA. (2013), Diagnostic and Statistical Manual of Mental Disorders, 5th ed., American Psychiatric Publishing, Washington, DC.
Astle, D.E. and Bathelt, J. (2019), "Remapping the cognitive and neural profiles of children who struggle at school", Developmental Science, Vol. 22, p. e12747.
Babikian, T., Merkley, T., Savage, R.C., Giza, C.C. and Levin, H. (2015), "Chronic Aspects of Pediatric Traumatic Brain Injury: Review of the Literature", Journal of Neurotrauma, Vol. 32 No. 23, pp. 1849–1860.
Biederman, J., Mick, E., Faraone, S. V, Braaten, E., Doyle, A., Spencer, T., Wilens, T.E., et al. (2002), "Influence of Gender on Attention Deficit Hyperactivity Disorder in Children Referred to a Psychiatric Clinic", American Journal of Psychiatry, Vol. 159 No. 1, pp. 36–42.
Bihlar Muld, B., Jokinen, J., Bölte, S. and Hirvikoski, T. (2015), "Long-term outcomes of pharmacologically treated versus non-treated adults with ADHD and substance use disorder: A naturalistic study", Journal of Substance Abuse Treatment, The Authors., Vol. 51, pp. 82–90.
Bishop, D.V.M., Whitehouse, A.J.O., Watt, H.J. and Line, E.A. (2008), "Autism and diagnostic substitution: evidence from a study of adults with a history of developmental language disorder", Developmental Medicine & Child Neurology, Vol. 50 No. 5, pp. 341–345.
Braiden, H.J., Bothwell, J. and Duffy, J. (2010), "Parents' experience of the diagnostic process for Autistic Spectrum Disorders", Child Care in Practice, Vol. 16 No. 4, pp. 377–389.
Bryan, K., Freer, J. and Furlong, C. (2007), "Language and communication difficulties in juvenile offenders", International Journal of Language and Communication Disorders, Vol. 42 No. 5, pp. 505–520.
Butwicka, A., Långström, N., Larsson, H., Lundström, S., Serlachius, E., Almqvist, C., Frisén, L., et al. (2017), "Increased Risk for Substance Use-Related Problems in Autism Spectrum Disorders: A Population-Based Cohort Study", Journal of Autism and Developmental Disorders, Springer US, Vol. 47 No. 1, pp. 80–89.
Capusan, A.J., Bendtsen, P., Marteinsdottir, I. and Larsson, H. (2019), "Comorbidity of adult ADHD and its subtypes with Substance Use Disorder in a large population-based epidemiological study", Journal of Attention Disorders, Vol. 23 No. 12, pp. 1416–1426.
Chang, H.K., Hsu, J.W., Wu, J.C., Huang, K.L., Chang, H.C., Bai, Y.M., Chen, T.J., et al. (2018), "Traumatic Brain Injury in early childhood and risk of Attention-Deficit/Hyperactivity Disorder and Autism Spectrum Disorder: a nationwide longitudinal study", Journal of Clinical Psychiatry, Vol. 79 No. 6, available at:https://doi.org/10.4088/JCP.17m11857.
Cleaton, M.A.M. and Kirby, A. (2018), "Why Do We Find it so Hard to Calculate the Burden of Neurodevelopmental Disorders?", Journal of Childhood & Developmental Disorders, Vol. 4 No. 3, pp. 1–20.
Conti-Ramsden, G., Simkin, Z. and Botting, N. (2006), "The prevalence of autistic spectrum disorders in adolescents with a history of specific language impairment (SLI)", Journal of Child Psychology and Psychiatry and Allied Disciplines, Vol. 47 No. 6, pp. 621–628.
Crane, L., Chester, J.W., Goddard, L., Henry, L.A. and Hill, E. (2016), "Experiences of autism diagnosis: A survey of over 1000 parents in the United Kingdom", Autism, Vol. 20 No. 2, pp. 153–162.
Creese, B. (2016), An Assessment of the English and Maths Skills Levels of Prisoners in England, London Review of Education, Vol. 14, London, UK, available at:https://doi.org/10.18546/LRE.14.3.02.
Day,A (2022), Disabling and criminalising systems? Understanding the experiences and challenges facing incarcerated, neurodivergent children in the education and youth justice systems in England. https://www.sciencedirect.com/science/article/pii/S2666353822000327
Dean, M., Harwood, R. and Kasari, C. (2017), "The art of camouflage: Gender differences in the social behaviors of girls and boys with autism spectrum disorder", Autism, Vol. 21 No. 6, pp. 678–689.
Dinkler et al (2017), Maltreatment-associated neurodevelopmental disorders: a co-twin control analysis, Journal of Child Psychology and Psychiatry,Vol.58 (6), p.691-701
Van Duijvenbode, N. and Vandernagel, J.E.L. (2019), "A systematic review of Substance Use (Disorder) in individuals with mild to borderline Intellectual Disability", European Addiction Research, Vol. 25 No. 6, pp. 263–282.
Engel, G.L. (1977), "The need for a new medical model: A challenge for biomedicine", Science, Vol. 196 No. 4286, pp. 129–136.
Engel, G.L. (1980), "The clinical application of the biopsychosocial model", American Journal of Psychiatry, Vol. 137 No. 5, pp. 535–544.
Farooq, R., Emerson, L.M., Keoghan, S. and Adamou, M. (2016), "Prevalence of adult ADHD in an all-female prison unit", ADHD Attention Deficit and Hyperactivity Disorders, Vol. 8 No. 2, pp. 113–119.
Fisher, M.H., Moskowitz, A.L. and Hodapp, R.M. (2013), "Differences in social vulnerability among individuals with Autism Spectrum Disorder, Williams syndrome, and Down syndrome", Research in Autism Spectrum Disorders, Elsevier Ltd, Vol. 7 No. 8, pp. 931–937.
Flory, K. and Lynam, D.R. (2003), "The relation between Attention Deficit Hyperactivity Disorder and substance abuse: What role does Conduct Disorder play?", Clinical Child and Family Psychology Review, Vol. 6 No. 1, pp. 1–16.
Fuller-Thomson, E., Carroll, S.Z. and Yang, W. (2018), "Suicide Attempts Among Individuals With Specific Learning Disorders: An Underrecognized Issue", Journal of Learning Disabilities, Vol. 51 No. 3, pp. 283–292.
Gershon, J. (2002), "A meta-analytic review of gender differences in ADHD", Journal of Attention Disorders, Vol. 5 No. 3, pp. 143–154.
Giannini, M.J., Bergmark, B., Kreshover, S., Elias, E., Plummer, C. and O'Keefe, E. (2010), "Understanding suicide and disability through three major disabling conditions: Intellectual disability, spinal cord injury, and multiple sclerosis", Disability and Health Journal, Vol. 3 No. 2, pp. 74–78.
Green, J.L., Rinehart, N., Anderson, V., Nicholson, J.M., Jongeling, B. and Sciberras, E. (2015), "Autism spectrum disorder symptoms in children with ADHD: A community-based study", Research in Developmental Disabilities, Elsevier Ltd., Vol. 47, pp. 175–184.
Gudjonsson, G.H., Sigurdsson, J.F., Bragason, O.O., Newton, A.K. and Einarsson, E. (2008), "Interrogative suggestibility, compliance and false confessions among prisoners and their relationship with Attention Deficit Hyperactivity Disorder (ADHD) symptoms", Psychological Medicine, Vol. 38 No. 7, pp. 1037–1044.
Gudjonsson, G.H., Sigurdsson, J.F., Sigfusdottir, I.D. and Young, S. (2012a), "False confessions to police and their relationship with conduct disorder, ADHD, and life adversity", Personality and Individual Differences, Vol. 52 No. 6, pp. 696–701.
Gudjonsson, G.H., Sigurdsson, J.F., Sigfusdottir, I.D. and Young, S. (2012b), "An epidemiological study of ADHD symptoms among young persons and the relationship with cigarette smoking, alcohol consumption and illicit drug use", Journal of Child Psychology and Psychiatry and Allied Disciplines, Vol. 53 No. 3, pp. 304–312.
Harpin, V. and Young, S. (2012), "The challenge of ADHD and youth offending", Cutting Edge Psychiatry in Practice, Vol. 2, pp. 138–143.
Harrop, C., Gulsrud, A. and Kasari, C. (2015), "Does gender moderate core deficits in ASD? An investigation into restricted and repetitive behaviours in girls and boys with ASD", Journal of Autism & Developmental Disorders, Vol. 45 No. 11, pp. 3644–3655.
Hiller, R.M., Young, R.L. and Weber, N. (2014), "Sex differences in Autism Spectrum Disorder based on DSM-5 criteria: evidence from clinician and teacher reporting", Journal of Abnormal Child Psychology, Vol. 42 No. 8, pp. 1381–1393.
Hirvikoski, T., Mittendorfer-Rutz, E., Boman, M., Larsson, H., Lichtenstein, P. and Bölte, S. (2016), "Premature mortality in autism spectrum disorder", British Journal of Psychiatry, Vol. 208 No. 3, pp. 232–238.
HM Inspector of Probation (2021), – Neurodiversity a whole Professor Amanda Kirby child approach for youth justicehttps://www.justiceinspectorates.gov.uk/hmiprobation/wp-content/uploads/sites/5/2021/07/Neurodiversity-AI.pdf
Hofvander, B., Delorme, R., Chaste, P., Nydén, A., Wentz, E., Ståhlberg, O., Herbrecht, E., et al. (2009), "Psychiatric and psychosocial problems in adults with normal-intelligence autism spectrum disorders", BMC Psychiatry, Vol. 9, pp. 1–9.
Hughes, N., Williams, H., Chitsabesan, P., Davies, R. and Mounce, L. (2012), Nobody Made the Connection: The Prevalence of Neurodisability in Young People Who Offend, London, UK, available at: https://yjlc.uk/wp-content/uploads/2015/03/Neurodisability_Report_FINAL_UPDATED__01_11_12.pdf.
Impey, M. and Heun, R. (2012), "Completed suicide, ideation and attempt in attention deficit hyperactivity disorder", Acta Psychiatrica Scandinavica, Vol. 125 No. 2, pp. 93–102.
Jawaid, A., Riby, D.M., Owens, J., White, S.W., Tarar, T. and Schulz, P.E. (2012), "'Too withdrawn' or 'too friendly': considering social vulnerability in two neuro-developmental disorders", Journal of Intellectual Disability Research, Vol. 56 No. 4, pp. 335–350.
Jones, L., Goddard, L., Hill, E.L., Henry, L.A. and Crane, L. (2014), "Experiences of Receiving a Diagnosis of Autism Spectrum Disorder: A Survey of Adults in the United Kingdom", Journal of Autism and Developmental Disorders, Vol. 44 No. 12, pp. 3033–3044.
Keenan, M., Dillenburger, K., Doherty, A., Byrne, T. and Gallagher, S. (2010), "The Experiences of Parents During Diagnosis and Forward Planning for Children with Autism Spectrum Disorder", Journal of Applied Research in Intellectual Disabilities, Vol. 23, pp. 390–397.

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