# Rationale and Evidence for Do-IT Profiler

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## Rationale for Do-IT Profiler

There is extensive evidence that neurodevelopmental conditions including Dyslexia, Dyscalculia, Developmental Coordination Disorder (DCD) Attention-Deficit/Hyperactivity Disorder (ADHD, including ADD), Autism Spectrum Disorder, Developmental Language Disorder (DLD, including speech and language difficulties) and Tic Disorders (including Tourette's Syndrome and Chronic Tic Disorder)co-occur and have a considerable impact on individual in childhood, and impact on educational and employment outcomes. Long-term follow-up, epidemiological and clinical studies have shown that adults with untreated ADHD, when compared to normal controls, experience higher rates of academic failure, low occupational status, increased risk of substance use disorders (tobacco, alcohol or drugs), accidents and delinquency, and have fewer social relationships or friends (Kooji et al, 2010).

### Prevalence of neurodivergent conditions

Neurodiversity is common within the general population. For example, among UK children estimates of the diagnosed prevalence of ADHD range from 0.5-2.2% whereas for Dyslexia these range from 2.3-6.2% (Cleaton and Kirby, 2018). The diagnosed prevalence of Neurodiverse conditions among children and young people in the UK ranges from 0.5-2.2% for ADHD to 2.3-6.2% for Dyslexia (Cleaton and Kirby, 2018).

### Defining conditions associated with neurodiversity

One of the key issues regarding Neurodiversity is that diagnosis is made on the basis of a set of symptoms – using, for example, include DSM-5 (APA, 2013) and ICD-10 (WHO, 1993) international sets of criteria. However, other factors, such as Adverse Childhood Experiences (ACEs, including childhood abuse) and head injuries (potentially causing Traumatic Brain Injury (TBI)) may also result in attention, concentration, social, memory, cognition and/or other difficulties that can mimic Neurodiverse conditions (Babikian et al., 2015; Chang et al., 2018; Van Der Kolk, 2005; Yang et al., 2016). Neurodiverse conditions, TBI and ACEs are also highly co-occurrent (Cleaton and Kirby, 2018) and symptoms of one may be misdiagnosed as another (e.g. Bishop et al., 2008).

Providing accurate, appropriate, and targeted support requires a comprehensive, person centred and holistic assessment.

## Lack of identification of some conditions associated with neurodiversity

Many Neurodiverse children and young people fail to have their Neurodivergent condition(s) diagnosed. Lack of identification may be attributable to the route to diagnosis. There are various routes to gaining a diagnosis of a Neurodevelopmental condition, which may be inconsistent and for some difficult to access (e.g. Jones et al., 2014). This is particularly true of individuals with multiple Neurodiverse conditions (Brett et al., 2016; Kentrou et al., 2018) and individuals with co-occurring Neurodiverse and mental health condition(s) (Barkley and Brown, 2014; Takara et al., 2015). It is also true of those coming from specific SES groups where their 'behaviour' may be attributed to trauma or social and emotional challenges rather than also importantly considering neurodiversity in the mix (Dinkler et al, 2017).

## Missed diagnoses

There are many reasons why a young person's Neurodivergent traits may be missed.

Parental engagement with health and educational services may be limited with school (Astle and Bathelt, 2019; Hamed et al., 2015). Some children may be or have been excluded from school and may move around the system (e.g. as a result of being a Looked After Child and/or Young Person (LACYP)) (Jacobson et al., 2010; Oak Foundation, 2019). One or more of these factors may result in the young person being less likely to have gained or gain a diagnosis.

There are continuing 'postcode lotteries' affecting the provision of diagnostic services in the UK (Lamb, 2018) and increasing waiting lists in many areas because of the impact of the pandemic.

The diagnosis an individual receives remains, in many cases, determined by the services provided by their local healthcare board (Ross, 2018), the knowledge and biases of their parents and of gatekeepers such as teachers and GPs (Miyasaka et al., 2018), the particular specialists that are seen (Astle and Bathelt, 2019) and the ability of the individual and/or their parents to access services (Keenan et al., 2010). In particular, some less well known conditions, such as DCD and DLD, often fail to be considered and assessments for these may be particularly difficult to access (Missiuna et al., 2006).

## Misdiagnosis

Misdiagnosis is also a potential issue affecting individuals with Neurodiverse conditions. For example, ADHD (Horton-Salway, 2011), ASD (Midence and O'Neill, 1999), DLD (Ripley and Yuill, 2005) and other Neurodiverse conditions are frequently misdiagnosed as 'bad behaviour'. In other cases, Neurodiversity may be misdiagnosed as another condition (e.g. Aggarwal and Angus, 2015). Confusion may also occur when history of head injury is not considered, as TBI can result in 'secondary' ADHD as well as symptoms that mimic ASD and ID (Babikian et al., 2015; Chang et al., 2018; Compton et al., 2017; Keenan et al., 2008; Max et al., 2005a, 2005b; Yang et al., 2016). In particular, some children may appear to 'recover' from their TBI(s), as the behavioural impact may not become apparent until adolescence (Tonks et al., 2017). In these cases, symptoms are infrequently correctly attributed to the TBI.

## Female populations

Females appear to be at particular risk of under- and misdiagnosis of Neurodiverse conditions, although so far this has only been investigated for ADHD (Nussbaum, 2012) and ASD (Loomes et al., 2017). Females with ADHD more often have the predominantly inattentive type (Biederman et al., 2002; Gershon, 2002), which is usually associated with less disruptive and externally-obvious symptoms (APA, 2013).

Females with ADHD are also less likely than males to exhibit physical aggression and other externalising behaviours (Rucklidge, 2010). Likewise, females with ASD generally present differently to males. They tend to have more age- and gender-typical restricted interests (Hiller et al., 2014) and often mimic peers' social interactions, although without necessarily understanding them (Dean et al., 2017; Lai et al., 2017). Additionally, females with ASD tend to have higher levels of social motivation (Sedgewick et al., 2016) and lower levels of repetitive behaviour (Harrop et al., 2015; Mandy et al., 2012; Van Wijngaarden-Cremers et al., 2014). These differences in presentation likely contribute to the under- and misdiagnosis of Neurodiverse females.

### Potential impact of missed diagnoses and misdiagnosis

Neurodiverse individuals typically experience cumulative adversity – increasing, accumulating negative experiences over time. This includes a range of poor psychosocial outcomes relating to offending behaviour, physical and mental health, education and employment (Cleaton and Kirby, 2018).

### Mental health and Neurodivergent conditions

Neurodivergent people are at increased risk of mental health difficulties (Cleaton and Kirby, 2018). These include common conditions such as Anxiety Disorders and Depression, but also a range of other conditions such as Eating Disorders, Obsessive-Compulsive Disorder, Personality Disorders and Schizophrenia (Cleaton and Kirby, 2018).

Neurodivergent conditions are also associated with elevated risk of suicide. Suicidal ideation, suicide attempts and suicide completion are all more frequent in individuals with ADHD (Impey and Heun, 2012) and individuals with ASD are 7.6 times as likely to die by suicide as general population controls (Hirvikoski et al., 2016). Individuals with Dyslexia and/or Dyscalculia are 2.2 times as likely as controls to have ever attempted suicide (Fuller-Thomson et al., 2018). As well as suicide attempts, Dyslexia is also associated with self-harm and suicidal ideation (Alexander-Passe, 2016), as is ID (Giannini et al., 2010).

## Current diagnostic and support systems

### Categorical or dimensional?

The current diagnostic systems categorise individuals as having distinct, categorical, symptom-based disorders (ADHD, ASD, Dyslexia, etc.). However, a categorical approach like this ignores the fact that Neurodiverse conditions appear to be inter-related and often cooccur with each other (Kaplan et al., 2006, 1998, 2001) as well as other common, potentially confounding factors such as TBI and ACEs. They also co-occur commonly with mental health conditions as well such as anxiety and depression.

As well as commonly co-occurring, Neurodiverse conditions also commonly exist at a sub-threshold level. This is because they are based on dimensional, not categorical characteristics – similarly to other human characteristics such as height, any cut-off between 'normal' or 'typical' and 'abnormal', 'disordered' or 'atypical' is arbitrary. It is quite common, for example, for individuals with ADHD or DLD to have what is described as 'Autistic tendencies' – i.e. sub-

threshold ASD (Conti-Ramsden et al., 2006; Green et al., 2015). Some individuals, despite having functional difficulties in many areas (e.g. attention, social communication, reading, mathematics, memory), do not reach the diagnostic threshold for any of the particular conditions associated with these difficulties.

Diagnostic thresholds can result in inequitable provision of support and services, as they mean diagnosis functions as an all-or-nothing model. They also rarely consider other contributing factors such as TBI, abuse experiences and family disadvantage when diagnosing. The cumulative challenges experienced by someone with symptoms of multiple Neurodiverse conditions at a sub-threshold level may be functionally more impairing than the challenges experienced by someone who meets diagnostic criteria for, and has symptoms of, a single condition only. However, without a diagnosis, individuals with subthreshold Neurodiverse conditions are rarely deemed eligible for educational or medical support even if their overall needs are potentially greater. In a prison context, this may be why so few people have received diagnosis – their pattern of needs doesn't fit the current, categorical service model.

## Working in silos

Another challenge facing Neurodiverse people is that services often operate in different professional silos. For example, Dyslexia, Dyscalculia and, to some extent, DCD 'sit' in education, ADHD often 'sits' in CAMH services and ID may be separated from both of these into Learning Disability provision. The diagnoses people receive may often reflect the professionals that they have seen rather than the actual difficulties that they have (Astle and Bathelt, 2019).

Working in silos and focusing on particular conditions has severe consequences, as many if not most Neurodiverse individuals have more than one Neurodiverse condition (Cleaton and Kirby, 2018). Even if all of an individual's diagnoses are, eventually, made, working in silos means delays may be exacerbated. For example, if a child with DCD, ASD and Dyslexia was referred to a clinic because of social communication concerns, they would (after reaching the top of the, typically very long, waiting list) receive a diagnosis of ASD. However, they would then have to be referred to a motor disorders clinic, with another very long waiting list, to be diagnosed with DCD. Later, perhaps after a few years at school, their reading difficulties might become increasingly obvious and they might be referred to an educational psychologist for a Dyslexia evaluation, with yet another long wait. By this point, years without adequate support could mean the child has developed nascent mental health difficulties, disaffection with school and/or a negative relationship with their parents. They may have spent years unable to access the curriculum, with long-term consequences for their educational and employment outcomes, as well as offending behaviour. In contrast, if they had initially been referred to a comprehensive Neurodiversity clinic, they could have been screened and monitored for all Neurodiverse conditions, resulting in timely diagnoses, earlier initiation of support and potentially better long-term outcomes.

## Trauma in childhood and neurodiversity

Dinkler et al in 2017 showed six times increase in having neurodevelopmental conditions such as ADHD in those subjected to child maltreatment compared with those children that have not had these childhood traumatic experiences. They showed an additive rather than causal effect.

## Data sharing gaps

Another issue associated with the separation of services into silos is that datasharing is frequently inadequate or variable if it happens at all. Thus, for example, in a prison context the mental health team may not inform the substance abuse team about an individual's ADHD diagnosis, even though this may affect their likelihood of drug relapse (Bihlar Muld et al., 2015) or sharing of information when leaving or entering a prison with GP services may be scant or variable.(Wright et al, 2019)

Equally, education may not inform either the mental health team or the substance abuse team about the individual's Dyslexia, resulting in the individual being given self-help materials that they cannot read.

This lack of joined-up thinking and working has the potential to severely affect people in prison.

All of the above models (i.e. single-condition 'siloed' services, LDD-specific services and services that rely on prior diagnosis/support to identify service users) are highly unlikely to be sufficiently comprehensive, equitable or fair. They fail to recognise the reality of the conditions they purport to assess – i.e. that Neurodiverse conditions are complex and interrelated, they have high levels of symptom commonality with other conditions such as TBI and they are frequently undiagnosed and misdiagnosed. Thus, these systems risk leaving the most needy individuals unidentified and unsupported, consequently rendering them highly vulnerable to within-prison victimisation, unlikely to cope with prison routines, unlikely to be able to access rehabilitative courses and at greater risk of reoffending (Bradley, 2009; Coates, 2016; Jacobson, 2008; Loucks, 2007a, 2007b; Loucks and Talbot, 2007; Talbot, 2007, 2008; Talbot and Riley, 2007). Unfortunately, these appear to be the predominant service models, both within the community and within the Justice Sector.

## Why take a person-centred and needs-led approach

Categorical approaches to the diagnosis and support of Neurodiverse individuals have many serious shortcomings. An alternative to these, are dimensional approaches – approaches which consider an individual's unique needs as a whole, rather than determining whether 10 the individual fits certain diagnostic criteria and providing support only if these diagnostic criteria are met. Dimensional approaches are needs-led rather than diagnosis-led.

A shift away from categorical approaches towards more holistic, profile-based, dimensional approaches have been suggested by some psychiatrists (NIMH, 2014). This approach creates a formulation-based assessment and management plan based on all of an individual's needs, whether they group neatly into diagnostic criteria or not. The key areas of challenge for that individual are identified with respect to their current social and physical environment and appropriate, holistic support is provided.

Dimensional approaches are also typically person-centred – they put the person first and consider them as an individual rather than a category or type. Person-centred approaches are often based on a biopsychosocial model of disability. This model incorporates the best aspects of two previous models of disability: the medical model and the social model (Engel, 1977, 1980). It is based on the idea that disability is the combination of differences in people's bodies (bio-), differences in people's minds (psycho-) and the mismatch between people's needs and the physical and social environment that they live in (social).

By taking person-centred approach using the biopsychosocial model, we can better support Neurodivergent people, resulting in better outcomes for all.

## Accessible and effective profiling of complex adversity

There is a clear need for timely, practical and comprehensive profiling using dimensional, needs-led, person-centred approached. This will allow parents and teachers to gain a thorough understanding each child's specific strengths and challenges. To do this, more holistic screening and support approaches are required, as needs and suitable interventions will vary between individuals (and over time).

One challenge to delivering this sort of approach to screening and support has been how to practically capture this information, especially if there are no specialists available to undertake this work.

Accessible, voiced, computer-based screening solutions can be self-administered and can automatically and immediately generate functional guidance as a first step to providing support. As scores and personalised initial support recommendations are automatically generated, the administrative burden of screening participants is greatly

reduced and the risk of errors during manual data-entry or scoring is eliminated. Computer based screening solutions allows for information to be easily communicated to relevant stakeholders across the prison, breaking down silos and allowing easier interdisciplinary working. Overall, they have the potential to rapidly, efficiently and comprehensively identify the most vulnerable.

This may save time and allow conversations about support needs and recommended interventions to occur earlier in an individual's pathway through the educational system, improving outcomes in this high-demand context.

## Content and design of Profiler

The approach taken with Do-IT Profiler is to understand the person in the context of their lives past and present and deliver contextual guidance dependent on the specific profile. This takes a bio-psychosocial approach embracing the learning from researchers in this field including Gillberg, Minnis, Sonuga-Barke and Thapar for example.

The system is set up in modules which the person completes or additional information is gathered from other sources where triangulation of information is relevant and further improves the data gathering.

Module content in each Profiler pack may be dependent on age and context. Each module is designed in the way it is presented dependent on this e.g.

• **Length of module** – this considers those who may have attention difficulties associated with ADHD
• **Content and layout design** – voicing and length of sentences are considered for those with challenges associated with Dyslexia, Literacy, Working memory.
• **Presentation of information** e.g., use of pictures and voicing may be dependent on age of the person
• **Item choice** – this is dependent on the specific screening e.g., neurodiversity screener has items that are related to specific cognitive areas. Development of items has been undertaken using Delphi consensus methods to agree content and then tested on typically developing mainstream and specific/clinical populations with known conditions.
• **Selected focal areas** – this has been drawn from work over the past 10 years by Smythe and Kirby with recognised research expertise in Neurodiversity.

Profiler does not attempt to draw comparisons with other learners/individuals by referring to age or grade equivalence as the aim is to identify the pattern of challenges within the individual to target support and guide provision.

It allows information to be gathered from differing viewpoints including to listening to the voice of the child/learner; from parents/partner where appropriate, and from other sources such as education to inform clinical decision making for example.

There are several reasons why a learner may fail to acquire (for example) good literacy skills for example, including:

• Dyslexia
• Non-attendance at school/Exclusion
• Speech and Language Delay
• English is not the first language
• Intellectual disability
• Lack of opportunity to be taught

A detailed assessment can help to identify the underlying cause(s), which can then aid the production of an Individual Education Plan (IEP) or Learning Plan. Our tool reduces the likelihood of deciding on a specific diagnosis just based on a single strand of information without opening a broader profile of that person's life both past and present.

This should provide a clear understanding of the strengths and weaknesses of the individual and describe the steps and strategies in how to improve each person's skills.

Profiler uses a combination of written and visual guides in individual reports. As a criterion based system, the primary reporting method are raw scores, with detailed error analyses.

To help management and monitor progress, Profiler converts these to four levels to flag levels of support needs and strengths.

- Good Skills(Green)
- Reasonable Skills (Blue)
- Some Challenges (Orange)
- Significant Challenges (Red)

By reviewing results across modules, it is possible to identify the areas of challenge and the order in which they should be addressed but also crucially understand other factors that may constraining success internally or externally.

The approach taken and testing in different settings can be seen from some of our publications as well as in some of our research bulletins.

## The Three R's – Results, Report, Recommendations

the Summary Report, which provide an overview of all modules that have been taken, complete with a skills appraisal. This can show strengths in an individual as well as areas of challenges that may need to be addressed.

For modules which assess specific skills an 'Errors Report' is provided that not only gives the answer given along with the score, but also the time taken. This can often be indicative of the fluency/automaticity of the skill in question.

Information is presented in different formats using visual guides, providing practical support and more in depth guidance.

# Relevant published papers and those relating to the content of the tools:


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