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Using data driven decision systems to deliver person-centred approaches in developmental disorders: one example of complexity - the criminal justice system

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Abstract

A carefully taken history can result in a correct medical diagnosis 90% of the time in skilled hands. It requires capturing information from the person's past history as well as current functioning and setting. However, where individuals may be moving in and out of systems inconsistently, this can be difficult to undertake as well as there being a lack of trained personnel for the task. Without consistent and robust systems in place wrong assumptions can be made and the result of partial information can be wrong or no support provided.

This paper describes an example of the challenges in the Criminal Justice System (CJS) in identifying and supporting individuals with a range of developmental disorders and learning difficulties. It provides an example of how using an innovative computerized accessible assessment system has assisted in screening and undertaking some assessments in order to make more accurate judgments and conclusions.

If we are to truly recognise and support the needs of offenders with developmental disorders. joined up systems are required from the point of entry into the CJS and that can work across prisons and into rehabilitation. However, technology is merely a tool to assist in this process and has to be a part of an embedded system. This means that the information gathered has to facilitate discussion and action, and the tools for tracking can aid monitoring and measuring outcomes. Every good car needs a competent driver who knows where they heading.

This requires a change in approach to allow a bio-psychosocial dimensional approach to be taken rather than a categorical approach. This needs barriers between professionals to be lowered in order to work in a trans-disciplinary fashion. CJS is one example, but other sectors such as education and Welfare to Work represent similar challenges for the identification and support of individuals with developmental disorders.

Introduction

> Most misunderstandings in the world could be avoided if people would simply take the time to ask, "What else could this mean?" (Alder)

As a medical doctor my training was grounded in taking a history in order to make a diagnosis. I was taught that a carefully taken history would result in the correct diagnosis 90% of the time and this approach in skilled hands has shown this rate (Peterson, 1992). However, this is challenging where there are people moving in and out of systems, and there is a lack of trained personnel to do this. This can result in missing and misdiagnosing individuals or even worse perhaps misunderstanding their behaviours. This paper describes the Criminal Justice System (CJS) as one example of this in the field of developmental disorders.

A number of documents in the past fifteen years have highlighted the need for supporting people with a range of developmental disorders and learning disabilities in the CJS. Reports include Valuing People (2001); The Prison Reform Trust series of No- one Knows reports (2007/8); Valuing People Now (2009); and The Bradley Report (2009). Determining accurately levels of developmental disorders in the CJS, for example Dyslexia, has led to wide prevalence levels being cited depending on the tools and definitions used being anywhere from 5-56%.

The reports have described the need for processes for early identification, use of appropriately designed screening tools, and an efficient system to deliver support and guidance as a consequence of any identified need. The Bradley Report published in 2009 described the challenge in using either self report or standardised measures and concludes neither provides a precise measure. The report says for example "IQ testing is often used as an indicator of the prevalence of learning disabilities; however, this is felt not to meet the full definition, as it does not consider any additional impairment of social functioning." (p.20).

Capturing a complete picture of the offender to deliver appropriate support has remained a challenge and without consistent and robust systems in place wrong assumptions can also be made. Macdonald (2012) focusing on levels of dyslexia in the CJS and discusses a 'chicken and egg' problem and the potential result of mislabelling or skewed prevalence rates being quoted. In the CJS this has been cited widely between 5-56%. There may be several reasons for an individual having reading difficulties. Samuelsson et al (2000) unlike some researchers, found that the frequency of dyslexic problems was very similar to that of the population at large and attributed a failure to read and spell to more experiential factors such as school history, attention problems, and reading habits. Lindgren, et al. (2002) attributed some reading difficulties to the high association with ADHD. Asbjørnsen, et al, (2008) agreed with the high levels that others had found in reading and writing difficulties but concluded that

this was also related to lack of experience and difficulties attending. A lack of schooling may lead to less opportunity for receiving teaching resulting in poor reading. An alternative proposition may in some be due to high levels of inattention and impulsivity leading to exclusion from school and thus missing teaching time. Alternatively, an individual with dyslexia, having challenges reading, may be less interested in school and also lead to exclusion. Add to this picture, Looked After Children (LAC) who often move from school to school, with or without additional learning needs, and one can see that the contribution of varying factors is often hard to disentangle and may be co-occurring, cumulative, or additive (Svensson, 2011).

A further example of a difficulty in teasing apart directionality of action with Attention Deficit Hyperactivity Disorder (ADHD) and Traumatic Brain Injury (TBI). Individuals with ADHD are at greater risk of accidents and risk taking behaviour, including road traffic accidents (Chang et al., 2014). Traumatic Brain Injury (TBI) has also been associated with symptoms of impulsivity and negative emotion rating (Vaughn et al., 2014). In an US study of juvenile offenders, one in three offenders had reported experiencing a head injury, causing them to be unconsciousness or needing medical attention, also consistent with a meta - analysis undertaken by Farrer et al., 2012.

Few offenders arrive for many of the above reasons 'labelled' with a learning difficulty or disability and may have been misdiagnosed. Some individuals may also have never had the opportunity for a diagnosis at school as having been excluded from school they may have missed out on traditional assessment pathways (Mottram and Lancaster, 2006). Assessment may also be dependent on the primary difficulty e.g. young people with a Specific Language Impairment (SLI) but not a diagnosis of Autism Spectrum Disorder (ASD) may have been seen to be less likely to have had assistance despite the impact of their difficulties on life being similar (Dockrell et al., 2012, Bryan, 2004). Extensive research also over the past 15 years has demonstrated that developmental disorders don't come in isolated 'boxes' but disorders such as ADHD, Dyslexia, Developmental Co-ordination Disorder (DCD), ASD and SLI co-occur and that the 'pure' individual is in fact a rare (e.g. Kaplan et al., 1998). Additionally, co-occurrence with mental health difficulties is also common e.g. ASD and anxiety (White et al. 2009). ADHD symptoms have been correlated with more severe depression, anxiety, and daytime sleepiness, and poorer quality of life (Chao et al., 2008) as have DCD (Kirby et al., 2013).

Capturing information on current and past social, educational and health experiences is also important if we are to support the 'whole person' otherwise false assumptions can be made. The mesh of factors including exclusion from school, and in the past being a Looked After Children (LAC) seems important to capture, if only to ensure that we change systems to minimise entry into the CJS. 85% of the young offenders in a study by Mottram & Lancaster (2006) had been excluded from school at some point, with 30% excluded more than ten times. Macdonald (2012) states that "The route into criminal behaviour is not due to

inherent biologically determined neurological processes, but rather due to structural and environmental issues". However, the tangled web is even more complex than this and the gene/environmental argument is not won by either side but is a complex mesh of multi-way interactions.

The challenge is how can this information be captured in a robust and consistent fashion when there are other barriers as well? The list is long and include for example staff time to deliver a process, staff understanding on the value of doing so, staff training needs on how to support individuals with barriers to learning, consistent systems for assessment, analysis, and reporting and then pathways for referral and/or intervention. At the present time, paper based systems require appropriately trained persons to collect the information, someone to enter and analyse the data and no integration between varying tools. This also doesn't result in an integrated person-centred plan.

In the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-V) criteria (2013), the section relating neurodevelopmental disorders makes an important point in relationship to using IQ for example as one strict measure for intellectual disability:

> IQ test scores are an approximations of conceptual functioning but may be insufficient to assess reasoning in real-life situations and mastery of practical tasks.", and goes on to say there is a need for assessment tools to be "normed for the individual's sociocultural background and native language" and that "co-occurring disorders may affect communication, language and or motor /sensory function may affect test scores. (p.37)

In clinical practice, two people with a similar diagnosis can vary greatly in terms of their current skills, abilities and challenges. Their intellectual ability is only one part of who they are. The ability to cope can be related to many factors such as: Level and pattern of co-occurrence with other developmental disorders, family level of support now or in the past; level of local service provision to support them when they leave the CJS; transport links to access services; age when they were diagnosed. Without understanding these many factors it is hard to plan accurately.

The Do-IT Profiler system

Extensive research has shown that it is rare to find the developmental disorders and intellectual disabilities such as ASD, Dyslexia, DCD, SLI, etc. to exist with no other co-occurring difficulties. One example of co-occurrence is work by Willcutt & Pennington (2000) where they showed 80% of children with ADHD, and 60% of children with Dyslexia met the criteria for at least one additional diagnosis. The co-occurrence between Learning Disability and ADHD and ASD has also been extensively demonstrated (e.g. LoVullo et al., 2009).

With growing recognition of this it thus seemed appropriate to develop screening tools that not only captured key elements across the developmental disorder to be able to check, but

also to provide some practical guidance depending on the profile of the individual, and in the context of the setting.

The aim of such tools was to be pragmatic and to deliver a more bio-psycho-social approach rather than one that had a narrower medical model as the evidence for complexity of presentation depending on the environment was also growing. The tools aimed to encompass the context of the individual, alongside the pattern of their strengths and challenges and assist in guiding the professionals who were supporting the individuals.

The development of the tools from paper format to computerised systems has been over a ten -year period, and started with development for use in colleges and prisons and with trials in three prisons in a paper based format in 2005/2006 (Smith and Kirby, 2006) and in a large college setting. After this initial testing phase the content was converted to a computerized versions (depending on the setting) and additional modules were added to it to gather information on demographics, and to gain information on background and relevant current social, educational and medical histories (Kirby and Smythe, 2015).By computerizing the system it also ensured that it consistent information is gathered. A modular approach also means that those with short attention spans can complete information in more than one sitting if necessary.

The Do-IT Profiler system is computerized modular screening and assessment system which delivers person-centred guidance depending on the setting, and identifying barriers to success whether in education, CJS or Welfare to Work. It has an inbuilt Management Information System (MIS) which automatically analyses all data and delivers a range of reports at individual, group and organisational levels. These can be exported in varying formats for further analysis or integration into other systems. The Profiler system has assessed 1000s' of individuals resulting in the data being available immediately modules have been completed. Additional modules have been developed such as to aid resettlement and for preparation for the workplace, along with assessments for literacy and numeracy, and mental wellbeing. A recent addition is a ten-minute assessment module with an aim to assist in screening for intellectual disability which is now being trialed.

The computer system delivers the tools in an accessible format (e.g. all questions are voiced, options to use coloured overlays, and to expand text size). There is minimal text entry and a spellchecker is built into the system. The system is being used in different ways in different prisons at the moment. In the case of one prison trained peer mentors (prisoners) support the delivery, in other prisons it is being used at the point of induction with groups of offenders.

The outputs and guidance for the CJS were developed followed extensive discussion with forensic psychologists and other staff members in the prison setting to ensure they are contextually appropriate and practical for both staff and offenders. It is further amended following feedback from the prisons. The staff care and support strategies are written to be

able to be implemented in line with the approach taken in "The Five Minute Intervention (FMI)" approach which encourages trained officers to turn everyday conversations into rehabilitative interventions. The offenders have a personalized report with 'strategies for success' and also access to a range of resources available as short videos, sound files and fact sheets to suit different styles of learners and their communication needs. The system also delivers an executive summary with a traffic light system, and pulls out key elements that may trigger further assessment and /or support. Algorithms have been developed to analyse data from different parts of the Profiler and deliver varying outputs.

The length of time to complete the commonly used modules is around 40 minutes, but as it is a modular system additional modules can be added such as for planning for resettlement, literacy battery of assessments, restorative justice modules and can be used at different points in an offender's journey through the CJS.

In some prisons that have used the system for some time the system has become embedded and also has been recognised as part of the good practice HMP Parc prison in Bridgend, one of the first prisons to use the system received a Butler Trust award in 2014 for the establishment of the Learning Disabilities Pathway, and for the unique initiative.

Data driven decision making

Lord Kelvin (1883) said "that when you can measure what you are speaking about, and express it in numbers, you know something about it; but when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind" (p.73).

By developing accessible processes to capture information meaningfully this can also be used to inform future practices and policies. However, until recently technological advances which allowed for such systems were not cost, time effective and accessible.

A real difference using the computer system is the integration of information and instant analysis at individual, meso and macro levels. This is in contrast to the use of paper based screening tools which often only create a score, and any detail of the precise responses and time for completion may be lost. These tools also don't usually provide tailored, contextualised or personalised guidance, and any associations with other information captured cannot be made or analysed unless they are inputted into a system and manpower allocated to do this task. This would be a challenge in the CJS. New knowledge gained by this process allows for example gaining better understanding of the association between learning difficulties and reported number of school exclusions, ADHD symptoms and TBI.

Without data, planning is very difficult to do. Recently in the publication in 2015 "Joint inspection of the treatment of offenders with learning disabilities within the criminal justice

system - phase two in custody and the community" there is continuing concern expressed that there needs to be better processes to provide adequate and appropriate support.

Since the implementation of the Profiler, now in 15 prisons, more than 4000 offenders have been screened, but this is not always as a part of an embedded system. Using the tool has not only provided the person-centred reports and system for flagging up individuals that may require additional help, but has also given access to large data sets which begin to be used to guide further development of support and service delivery. Examples of live information gained include individuals excluded at school; Looked After Child status; number diagnosed with ASD, ADHD, etc. and who have accessed additional help and much more. The advantage of capturing this information within the system allows for correlations to be easily made with other data sets e.g. offending type, age, gender, level of current social and communication difficulties, past educational support.

Some modules within the system are also used in other settings and so have the potential to compare different groups e.g. in Further Education, among those Not in Education, Employment, or Training (known as NEETS), Welfare to Work settings and be able to map out commonalities and differences providing exciting research opportunities.

However, there remains a need to upskill staff in recognising and supporting individuals with developmental disorders and learning difficulties in the CJS. There is little use parachuting a system or tools into a prison without gaining 'buy in' and the outcomes from completing these processes need to be meaningful to the staff using them. Alongside the use of the Profiler and the system described, staff require training about learning difficulties and disabilities. A cascade training programme has now been delivered in several prisons providing information and practical strategies.

Future steps

Technology allows a means of delivering information in different formats allowing for flexibility and constant improvements to be made as new learning is gained. The Profiler tools are now being used in 15 prisons in the UK. As a consequence of consultation with prison staff further adaptations have been made since its inception, for example recording use of the Welsh Safe Card scheme in the Welsh version, and the system has been translated into Welsh. (Other languages can now be added into the system). An 'app' version has been developed for community settings to be used on tablets to allow on and offline usage in community settings such as in police custody suites and to be able to measure 'distance travelled measures' in soft and specific skills.

Conclusions

If we are to truly recognise and support the needs of offenders with developmental disorders. joined up systems are required from the point of entry into the CJS and that can work across prisons and into rehabilitation. Information sharing protocols need to be delivered to minimise the need for the individual to 'retell their story' again and again and also to capture vital pieces of the jigsaw to make appropriate and meaningful interventions. Technology is a tool to assist in this process and has to fit into a system. This requires a change in approach to allow a bio-psychosocial dimensional approach to be taken rather than a categorical approach. This needs barriers between professionals to be lowered in order to work in a trans-disciplinary fashion. CJS is one example, but other sectors such as education and Welfare to Work represent similar challenges for the identification and support of individuals with developmental disorders.

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