Impact case study (REF3b)



Institution: University of South Wales

Unit of Assessment: A4

Title of case study:

The development of the first adult screening tool for Developmental Coordination Disorder: the Adult Developmental coordination disorder Checklist (ADC)

1. Summary of the impact

The Adult Developmental coordination disorder Checklist (ADC) is the first screening tool developed specifically to identify the difficulties experienced by adults with Developmental Coordination Disorder (DCD).

DCD was previously regarded as a childhood disorder. However, increasing evidence suggests that the motor difficulties experienced persist into adulthood. Previously, little information was being collected about how these difficulties present in adulthood or their impact on everyday living and there was no standardised screening tools for assessing the level of functional impairment.

The key impact of the ADC is that it is currently being used clinically nationally and internationally to clarify target areas for support.

2. Underpinning research

Amanda Kirby and her team at The Dyscovery Centre have, since its inception in 1997, conducted ground breaking research into DCD and other neurodevelopmental disorders. The team have produced over 50 peer-review journal articles within this area and presented at conferences nationally and internationally. Originally, work at the Centre included the development of research methodologies for the management and support of children and families with DCD and related disorders which has established models of practice recognised worldwide. Early work also focussed on raising awareness among health and educational professionals with knowledge transfer initially occurred through training, developing accredited courses and producing books. Professor Kirby was also awarded a grant from GlaxoSmithKline to provide training for general practitioners across the UK and from the Novartis Foundation to organise an international symposium on DCD.

DCD (an impairment of motor coordination) has a marked impact on both academic and day-to-day living activities. Prevalence rates in schoolchildren have been estimated at 5% and recognised more often in boys than girls. Around 2-4% of the population are seriously affected by DCD but, despite its relatively high prevalence, there is less awareness of DCD than other conditions such as autism spectrum disorder (ASD).

Whilst a diagnosis of DCD in childhood usually brings with it access to support (at home and school), assistance may be reduced considerably with the transition to adolescence and adulthood alongside a greater need to be organised and independent. As youngsters with DCD move from education into employment, they are faced with new challenges and difficulties, less understanding by others and reduced access to professional guidance.

Although it is acknowledged that the impairments associated with DCD continue into adulthood, there was limited research into their impact on everyday living and no standardised screening tools for evaluating or characterising the functional deficits present. Previous studies had adapted measures used in childhood with varying results making it difficult to accurately assess the prevalence of DCD in adulthood. The lack of screening tools also presents a problem to clinicians when presented with an adult, with motor problems, who was not diagnosed with DCD in childhood. Although it is possible to apply diagnostic criteria to adults with some minor amendments, this does not reflect the pattern of presentation in adults or how difficulties impact on the individual's life. There was, therefore, a need to develop a valid and reliable tool to identify adults at risk for DCD for research and clinical use and to establish a basis for appropriate intervention. Thus, Professor Kirby and her team set out to develop the first screening tool that would have a clear positive

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impact on clinicians in terms of being able to accurately identify on individuals with DCD who would in turn receive more accurate, complete and appropriate support.

The development of the ADC was a collaborative project between The Dyscovery Centre, David Sugden (University of Leeds) and Sara Rosenblum (University of Haifa). It continues to be used by clinicians, researchers and individuals with DCD both nationally and internationally.

3. References to the research

Kirby, A. (2002). What happens to children with DCD when they grow up? Dyspraxia Foundation Professional Journal, 1, 3-6.

Kirby, A. (2004). The adolescent with developmental co-ordination disorder. London: Jessica Kingsley Press ISBN 1-84310-178-5.

Kirby, A. (2006). A longer term view of DCD- emerging adulthood. Dyspraxia Foundation Professional Journal, 5, 13-24.

Kirby, A., Sugden, D., Beveridge, S. & Edwards, L. (2008). Developmental Coordination Disorder (DCD) in adolescents and adults in further and higher education. Journal of Research in Educational Needs, 8,120-131.

Kirby A. & Rosenblum, S. (2008) The Adult Developmental Coordination Disorder/ Dyspraxia Checklist (ADC) for Further and Higher Education.

http://www.newport.ac.uk/research/researchcentres/Centres/Dyscovery

Centre/Research/Screening Tools - Adults/Documents/The questionnaire - The Adult DCD Dyspraxia Checklist.pdf

Kirby A., Edwards L., Sugden D., Rosenblum S. (2010). The development and standardization of the Adult Developmental Co-ordination Disorders/Dyspraxia Checklist (ADC). Research in Developmental Disabilities, 31 (1), pp. 131-139.

4. Details of the impact

DCD and overlapping developmental disorders have been the main theme of research at The Dyscovery Centre since its inception over 16 years ago by its founder and General Practitioner Professor Amanda Kirby. The Dyscovery Centre has built up an interdisciplinary team of health and educational professionals who run a service integrating different models of working as well as providing care for over three thousand children (mainly from the UK). It is acknowledged as a tertiary referral centre and receives referrals from paediatricians and child and adolescent psychiatrists from the National Health Service, and is recommended by a number of organisations including the Royal College of Speech and Language Therapists. The Centre's reputation has grown over the years and referrals now range from countries such as Japan, Singapore, Dubai, Ireland, USA, Russia and India. The Centre's clinical activity provides a sound basis for its continuing research.

Work at the centre has focused increasingly on 'growing up' with a developmental disorder and the impact this has on the individual and their families. This has produced seminal work in the field that the Centre remains known for. Using knowledge transfer principles is a central tenet of the work of the team and is a key objective throughout all research work undertaken at the centre. This has been achieved through translation of materials for differing audiences and in a variety of ways including using new media formats such as mobile phone applications, web sites and ebooks as well as the more traditional books and leaflets. The Centre prides itself on its engagement in mainstream and peer reviewed journals and through presentations, conferences and on television and radio programmes and newspaper articles.

The Adult Developmental coordination disorder Checklist (ADC) is routinely used in the day-to-day clinical activity of The Dyscovery Centre, having an impact on clinical decisions for 60 clients since its publication in September 2010. Adults referred to the clinic complete the screening tool to assist clinicians when diagnosing DCD. The screening tool provides insight into and understanding of areas that were reported in childhood along with current areas of difficulty for younger and older adults. This was not fully possible prior to its development - again demonstrating the positive and

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important impact that the ADC has had. There are four areas that are assessed: (a) past difficulties in childhood, (b) motor difficulties, (c) impairments in executive functioning skills, and (d) problems relating to social behaviour. The ADC is also freely available on the University of South Wales (via http://psychology.research.southwales.ac.uk/) where it is accessed by health and education professionals as well as individuals with DCD. The screener has received 2, 272 page views between the time it was uploaded onto the centre's clinical services web pages in September 2010 and May 2013. Those viewing the screener during this timeframe come from across the UK (2, 033) and also from Ireland (129), Belgium (92) and Australia (18) (taken from Google analytics data).

The ADC is currently used as a screening tool by Student Support Services in several universities in the UK and Ireland. For example it is routinely used as a screener for motor difficulties by student support services at the University of Cambridge. Here it acts to facilitate directed support to individual students. It is also recommended as a screening tool for use by universities in the UK by the group Movement Matters (see reference to the web link in section 5).

The ADC has been used in research projects in the UK and internationally to screen adult participants including: Oxford Brooks University, Eastern Michigan University, the Radbound University, Nijmegen Medical Centre, and Hôpital de la Salpétière. The ADC has also been translated into Hebrew, Dutch, Brazilian and Taiwanese where it has been normed in those countries for use in adults. It is also available on a new international website for research in DCD which can be accessed by experts in 29 countries (see reference to web link in section 5). A shortened version of the screening tool is also available on the 'NeuroKnowHow' neurodiversity web site (see reference to web link in section 5). The ADC has also been cited as a screening tool for DCD peer-review articles and books (see reference list in section 5).

5. Sources to corroborate the impact

Websites for ADC:

http://www.newport.ac.uk/research/researchcentres/Centres/Dyscovery Centre/Clinical Services/Pages/default.aspx

http://www.movementmattersuk.org/dcd-dyspraxia-adhd-spld/developmental-disorders-documentation/fe-and-he-guidance-.aspx

http://www.neuroknowhow.com/online-adult-dyspraxia-screening-checklist/

Universities using ADC: Supporting evidence will be provided from Universities in the UK and Ireland that are using the ADC. One example is the University of Cambridge where the ADC is used during disability assessments conducted by the Disability Resource Centre (key contact: Disabilities Adviser (Specific Learning Difficulties), Disability Resource Centre.

Translation of the ADC: Translated versions of the ADC will be provided.

Books/articles citing ADC:

McLoughlin and Leather (2013). The Dyslexic Adult: Interventions and Outcomes - An Evidence-Based Approach. British Psychological Society and John Wiley and Sons Itd.

Wilmut, K., Byrne, M. & Barnett, A. L. (2013) Reaching to throw compared to reaching to place: A comparison across individuals with and without Developmental Coordination Disorder. Research in Developmental Disabilities, 34(1), 174–182.

Barnett, A.L., Henderson, S.E., Scheib, B., Schulz, J. (2011) Handwriting Difficulties and Their Assessment in Young Adults with DCD: Extension of the DASH for 17-to 25-Year-Olds Journal of Adult Development 18 (3), pp. 114-121.