

Institution: University of Northumbria at Newcastle		
Unit of Assessment: 4 (Psychology, Psychiatry and Neuroscience)		
Title of case study: Changes to policy, practice, and support: the positive impact of screening questionnaires for intellectual disability		
Period when the underpinning research was undertaken: 2015 - 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Karen McKenzie	Professor	01/07/2014 – Present
George Murray	Professor	17/10/2016 – 31/08/2018
Rachel Martin	Research Assistant	01/04/2016 – Present
Period when the claimed impact occurred: 2015 – 2020		
Is this case study continued from a case study submitted in 2014? N		
1. Summary of the impact (indicative maximum 100 words)		
<p>Early identification of intellectual disabilities is crucial to ensure individuals receive appropriate support, maximising life chances, and minimising negative outcomes. However, many people experience delayed or missed diagnosis. Research from Northumbria University – through the refinement and validation of two screening tools to diagnose intellectual disabilities – has enabled more timely diagnosis of an intellectual disability. Importantly, unlike previously used diagnostic tools, these screening tools can be administered by non-professionals within hard-to-reach populations. They have been recommended and used by key healthcare organisations in the UK (Royal College of Nursing, Royal College of Psychiatry, and Public Health England) and internationally, most notably in Australia. This has facilitated the screening of over 7,500 otherwise unassessed prisoners, young offenders, and victims of crime in the UK and Australia and allowed those identified with an intellectual disability to be referred for extra assessments and support.</p>		
2. Underpinning research (indicative maximum 500 words)		
<p>People with an intellectual disability (or learning disability) face many challenges, including health inequalities and increased risk of homelessness and imprisonment. Early identification of intellectual disability is crucial to ensure individuals receive appropriate support, maximising life chances and minimising negative outcomes, yet missed and delayed identification of intellectual disability is common. In order to make this process more efficient, the Learning Disability Screening Questionnaire (LDSQ) and Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) screening tools were developed by Professor Karen McKenzie when working in the NHS. An ongoing problem, however, was the need for further studies to refine and, crucially, to validate the effectiveness and benefits of these diagnostic tools. After joining Northumbria University in 2014, McKenzie led new quantitative research to enhance and demonstrate the full potential of the LDSQ and CAIDS-Q screening questionnaires, to both extend their versatility and reach [R1-R6].</p> <p>Diagnosis of intellectual disability is time-consuming and requires assessment by trained professional psychologists, e.g., using the gold standard Wechsler Adult Intelligence Scales (WAIS) for adults and the Wechsler Intelligence Scales for Children (WISC) for children. The LDSQ and CAIDS-Q questionnaires are used as screening tools to help identify people likely to have an intellectual disability. They are composed of short questions (e.g., an individual's ability to tell the time or read) and allow a percentage score to be calculated from the answers. These screening tools provide an accurate, quick, easy to use identification of people who are likely to have an intellectual disability so that they can be referred for further assessment. Importantly, the tools can be administered by anyone. Research by McKenzie and colleagues at Northumbria re-assessed the LDSQ in 2015 against the updated 4th edition, WAIS-IV (the most recent version</p>		

of WAIS), to confirm it was still suitable and valid for use [R1]. The research team also used a multi-group item response theory approach (a widely used model that analyses data from different groups) to test the LDSQ for gender bias. In a sample of 211 males and 132 females, results showed that gender did not influence the outcome of the screening tool [R2].

McKenzie's research has refined and improved the screening tools to extend their versatility and reach. Whereas previously the CAIDS-Q had only determined if a child was 'likely' or 'not likely' to have an intellectual disability, McKenzie developed a method to convert a CAIDS-Q score to an IQ score, making it more useful for clinicians and even providing an alternative IQ estimation method in circumstances where full intellectual assessments are not feasible [R3]. In 2019, McKenzie and Murray validated the CAIDS-Q for use in NHS paediatric services (often the first point of contact for a child who may have an intellectual disability) by comparing it against commonly used assessments within clinical practice: WISC-IV and the Adaptive Behaviour Assessment System 2nd/3rd edition. This study illustrated the strong psychometric properties and high accuracy of the CAIDS-Q in this setting as it correctly identified all children that were already known, or subsequently found, to have an intellectual disability (54/181) through gold standard assessment [R4].

McKenzie and Murray explored the potential benefits of using the screening tools with hard-to-reach populations, particularly within homeless services [R5]. This qualitative study used semi-structured interviews (n=24) with staff and service users to identify support needs of homeless people with an intellectual disability, and the role that the LDSQ could play in such a setting. The LDSQ was considered to have many benefits: it could identify potentially highly vulnerable people, enable the provision of tailored support, and facilitate access to specialist services [R5]. Such benefits have also been identified in other services including healthcare (specifically intellectual disability and midwifery), education, and social work [R6].

3. References to the research (indicative maximum of six references)

R1. Karen McKenzie, Sharples, P.*, and Murray, A.L. (2015)** 'Validating the Learning Disability Screening Questionnaire against the WAIS IV' *Intellectual and Developmental Disabilities* **53** (4): 301-307 <https://doi.org/10.1352/1934-9556-53.4.301>

R2. Murray, A.L., Booth, T.**, and Karen McKenzie (2015)** 'An analysis of differential item functioning by gender in the Learning Disability Screening Questionnaire (LDSQ)' *Research in Developmental Disabilities* **39**: 76-82 <https://doi.org/10.1016/j.ridd.2014.12.006>

R3. Karen McKenzie and Murray, A.L. (2015)** 'Evaluating the use of the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) to estimate IQ in children with low intellectual ability' *Research in Developmental Disabilities* **37**: 31-6 <https://doi.org/10.1016/j.ridd.2014.11.001>

R4. Karen McKenzie, George Murray *, Murray, A.L., Delahunty, L.***, Hutton, L., Murray, K.****, and O'Hare, A.** (2019)** 'Child and Adolescent Intellectual Disability Screening Questionnaire to identify children with intellectual disability' *Developmental Medicine and Child Neurology* **61** (4): 444-450 <https://doi.org/10.1111/dmcn.13998>

R5. Karen McKenzie, George Murray, Wilson, H.**, and Delahunty, L.*** (2019)** 'Homelessness – 'It will crumble men': The views of staff and service users about facilitating the identification and support of people with an intellectual disability in homeless services' *Health and Social Care in the Community* **27** (4): e514-e521 <https://doi.org/10.1111/hsc.12750>

R6. Karen McKenzie, George Murray, Murray, A.L.*, and Rachel Martin (2019) 'The impact of an adult intellectual disability screening questionnaire on service providers and users' *Journal of Applied Research in Intellectual Disabilities* **33** (3): 457-464 <https://doi.org/10.1111/jar.12687>

*University of Glasgow; **University of Edinburgh; ***NHS Lothian and University of Edinburgh dual role; **University of Edinburgh; ****Edinburgh Napier; *****NHS Borders

*Additional Consultant roles: August 2015 – July 2016, November 2018 – October 2020

4. Details of the impact (indicative maximum 750 words)

Northumbria's research extended the validity, reliability, versatility, and positive impact of the LDSQ and CAIDS-Q screening tools, led to policy and practice change across a wide range of services in the UK and internationally, and increased use of the CAIDS-Q and LDSQ. This has had a direct impact on individuals living with intellectual disabilities as diagnosis has enabled them to access support and improve wellbeing and life chances.

4.1 Improved support for people living with intellectual disabilities and their carers

The LDSQ and CAIDS-Q have helped identify vulnerable people who were not previously known to have an intellectual disability, enabling them to receive appropriate support and adjustments. Recent research indicates that over 60% of staff and service users across a variety of settings felt that the CAIDS-Q or LDSQ had helped identify the person's support needs more quickly, resulted in increased support, and improved the person's wellbeing and life chances [E1, p5].

The CAIDS-Q is now available online on the UK-based Learning Disability Matters for Families WebApp [E2] (a toolkit developed by the NHS North East & Cumbria Learning Disability Network) and provides resources to families and professionals in relation to intellectual disability. Dr Karen Horridge, Consultant Paediatrician (Disability), notes: *'The inclusion of the CAIDS-Q has allowed...immediate feedback on whether the child/young person is likely to have a learning disability or not. The person is then signposted to sources of support, if required. There is no equivalent evidence-based measure available elsewhere'* [E3]. Over 500 people used the CAIDS-Q in just the first few weeks after its launch in 2020 [E3]. Dr Horridge highlights that:

'The CAIDS-Q helps to ensure that more children receive a timely diagnosis, and that those children who are most likely to have a learning disability received further assessment. As well as being freely available to those accessing the WebApp, the CAIDS-Q is used as part of routine practice by many paediatricians and other professionals' [E3].

4.2 Incorporation of the LDSQ and CAIDS-Q into policy and practice

The LDSQ and CAIDS-Q screening tools have been recommended by a range of high-profile bodies in the UK, including the Royal College of Nursing, HM Inspectorate of Probation and HM Inspectorate of Prisons, and the Royal College of Psychiatry [E1, p4-5]. The screening tools are now embedded in service pathways across the UK. Health Education England [E4, p7] and at least 130 NHS health boards and council areas in the UK use the tools to support referrals. Internationally, the tools are used in New Zealand, Norway, the USA, and Australia (e.g., the Australian Senate Community Affairs Reference Committee and the Cultural and Indigenous Research Centre Australia report using the CAIDS-Q to facilitate referral to clinical services for assessment) [E1, p6].

The screening tools have been found to be of particular use in the criminal justice system. Since 2015, at least 22 prisons across the UK have been using the LDSQ to identify prisoners with a possible intellectual disability [E5], including HMP Brinsford [E1, p5] and HMP Aylesbury [E6, p16]. The LDSQ is also used by the police and probation services in Thames Valley, Gloucestershire, and Birmingham [E5]. Jenny Talbot from the Prison Reform Trust states:

'The LDSQ is quick, accurate and easy to use (and does not need the person using it to have a professional training), which means that it has been integrated into settings where it would otherwise be difficult to screen for learning disability [...identifying learning disabilities at an early stage of the criminal justice system] enables those who might have a learning disability, and who are therefore at increased vulnerability and risk, to be identified in a timely way and receive additional support and assessment as required, for example, identifying the need for an Appropriate Adult, provision of tailored interventions, and accessible information and resources' [E5].

Further to this, the LDSQ is routinely used in the service pathways of NHS Trusts and other organisations that provide health and social care to criminal justice services, and those who have been victims of crime, in Yorkshire and Humber, Ashton, Leigh and Wigan Community Healthcare NHS Trust, Cumbria Partnership NHS Foundation Trust, Birmingham Community Healthcare, Wigan Council, Surrey Autism Partnership Board, Manchester University NHS Foundation Trust, and Oxleas NHS Foundation Trust [E5].

Criminal justice services using the LDSQ report several benefits of this tool over others, including quick, reliable identification of people with an intellectual disability, and more detailed – fewer inappropriate – referrals [E7, p22]. The scale at which individuals are being assessed and referred using the LDSQ is exemplified by data from Birmingham NHS Healthcare’s Community Forensic Team, who screened 6,683 people using the LDSQ between 2015-2018, of whom 2,963 individuals were referred for further support [E7, p18].

The LDSQ screening tool is also used to support victims of crime – most notably within Saint Mary’s Sexual Assault Referral Centre (SARC), a service in Manchester, UK, for victims of rape or sexual assault. The SARC routinely uses the LDSQ to assess victims for likely intellectual disability and consequently ensure they receive appropriate support to meet their needs. This is a particularly important tool for this service as pilot studies using the LDSQ revealed that on average 1 in 12 individuals using the service have an intellectual disability and require specialist support [E8, p2]. A press release from SARC in 2020 highlights that the data gained from the LDSQ is making the organisation ‘*start to think about how services should be tailored for people with learning difficulties. For instance, the LDSQ score can be routinely shared with the police who can arrange additional support...such as representatives who can advocate on their behalf*’ [E8, p2].

This impact is not limited to the UK. The SARC’s work with the LDSQ is being replicated by counterpart organisations in Australia [E8, p3]. Further, youth justice programmes in the state of New South Wales (NSW) in Australia are using the CAIDS-Q screening tool to assess all those who participate in Youth on Track (YoT) – an early intervention programme aimed at reducing offending rates among young people, funded by the Department of Communities and Justice – totalling around 350 individuals a year [E9]. Mandy Loundar, manager at Youth Justice NSW, states that the benefits of using the CAIDS-Q are that it is ‘*accessible and easy to use with the young people with complex needs by YoT caseworkers*’ [E9]. Loundar is also clear that CAIDS-Q leads to more constructive relationships with service users as it reminds caseworkers that young people ‘*may have a disability instead of their behaviour being simply seen as “bad” behaviour*’ [E9]. The CAIDS-Q is also being used in other areas of Australia, such as Victoria [E9]. The tool has been recommended by the Victorian Auditor-General’s Office [E1, p4-5] and was incorporated into Victoria’s Youth Justice Strategic Plan 2020-2030 [E10, p38].

5. Sources to corroborate the impact (indicative maximum of 10 references)

Ref.	Source of corroboration	Link to claimed impact
E1	McKenzie, K. <i>et al.</i> (2020) ‘The use of an impact questionnaire as a framework to evaluate the impact of research on policy and practice: screening questionnaires for intellectual disability’ <i>Research Evaluation</i> 1-13 https://doi.org/10.1093/reseval/rvaa019	Summary of the range of impacts of the LDSQ and CAIDS-Q on policy and practice in the UK and internationally
E2	CAIDS-Q WebApp Screenshots – 2a) first page and 2b) results page	Confirms inclusion of the CAIDS-Q on the Learning Disability Matters website
E3	Testimonial - Dr Karen Horridge, Consultant Paediatrician (Disability)	Confirms the availability and use of the CAIDS-Q at Learning Disability Matters and the benefits of its use by professionals and families

Impact case study (REF3)

E4	Health Education England (2018). Providing community forensic services for people with Learning Disabilities and/or Autistic Spectrum Conditions Workforce Competency Framework.	Confirms recommended use of the LDSQ as a tool to help diagnosis, as part of competency framework for community forensic services, including homeless services. p12 [NB 'quotient' used instead of 'questionnaire']
E5	Testimonial - Jenny Talbot, Prison Reform Trust	Confirms the use of LDSQ in UK prisons, police and probation services
E6	Quality Network for Prison Mental Health Services Annual Report Cycle 4, 2018-2019	Reports on the use of the LDSQ in HMP Aylesbury
E7	The Role of a LD Practitioner in Birmingham Liaison & Diversion Team (April 2019) Presentation Slides	Confirms the use of the LDSQ as part of the Liaison and Diversion pathway and the associated benefits
E8	Saint Mary's Sexual Assault Referral Centre (SARC) press release (accessed 08.10.20)	Confirms use of the LDSQ at SARC, associated benefits for sexual assault victims and work with Australia
E9	Testimonial - Mandy Loundar, Manager, Strategic Projects, Youth Justice New South Wales, Australia	Confirms use of CAIDS-Q in Youth on Track programme and numbers screened
E10	Youth Justice Strategic Plan 2020-2030	Confirms embedding of CAIDS-Q into strategy