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The use of an impact framework to evaluate the impact of research on policy and practice: screening questionnaires for intellectual disability

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Abstract

There is an increasing emphasis on the importance of research having an impact on policy and practice. This can be more difficult to evidence in intellectual disability services because of the wide range of stakeholders involved. We evaluated whether an impact questionnaire covering: knowledge production, capacity building, informing policy and practice, social and economic benefits could successfully be used to evaluate the impact of research into and use of two screening questionnaires: the Learning Disability Screening Questionnaire (LDSQ) and Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q). We conducted an online search for published peer reviewed and grey literature, and internet resources that referenced LDSQ and/or CAIDS-Q. The resultant literature and resources were assessed for relevance and organised according to the categories outlined in the impact questionnaire. Evidence was found for all the areas of impact, with the largest body of evidence being in relation to informing policy and practice and social benefits and the least

for economic benefits. The impact questionnaire provided the basis for a comprehensive and useful evaluative framework to assess impact, although there was some overlap between the different categories. The process of using it highlighted some wider issues to consider when attempting to evaluate impact. The results indicated that the research underpinning the LDSQ and CAIDS-Q had resulted in significant, generally positive, and wide-reaching impact on policy and practice in intellectual disability and other services, resulting in a number of positive outcomes.

Keywords: intellectual disability; screening; impact; policy; practice; evaluation

1. Introduction

There is an increasing emphasis on the need for research to have impact, particularly in the area of health, which has long been underpinned by the principle of evidence-based practice (e.g. Corner and Glasper, 2015). Research impact is formally measured in the UK by the Research Excellence Framework (REF) and was originally defined ‘as an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia’ (REF, 2011, p26). In 2021, the REF will assess the impact of research in terms of the ‘reach and significance’ on a number of areas including ‘economy, society, culture, public policy or services, health, the environment or quality of life’ (REF, 2019, p40).

Translating research into policy and/or changes in practice can, however, be difficult, meaning that the potential health and other benefits may be delayed or lost. A number of reasons for this have been identified including limited, passive or ineffective dissemination of research results (Brownson et al., 2018), addressing research questions that are not seen as important or relevant to policy makers and other stakeholders (Woolf et al., 2015), and limited evaluation of which activities are most effective for promoting knowledge transfer (McLean et al., 2018).

The internet increasingly offers a means to identify research impact by illustrating the reach and significance of the research in question through mentions in websites, grey literature and published literature. To help facilitate the assessment of such impact researchers have developed tools ranging from frameworks (Buxton and Hanney, 1996; McLean et al., 2018) to impact questionnaires (Solans-Domenech et al., 2019).

A commonly used method to evaluate impact is the ‘Payback Framework’ which was developed by Buxton and Hanney (1996). This comprises a logic model of the different

stages of a research project from initial conception through to impact with five associated categories of impact. These are: benefits to knowledge, future research (e.g. increasing capacity of new researchers), policy, health and health systems, as well as wider economic benefits. The framework can be populated either through surveys with researchers or through the generation of case studies based on different sources of evidence of impact (Hanney et al., 2017). This framework partly informed the development of the REF assessment of research impact (Hanney et al., 2017) and underpinned the structure of the impact questionnaire developed by Solans-Domenech and colleagues (2019).

The latter group aimed to develop a questionnaire that would have internal reliability and content validity, when used by researchers across different research areas to self-report the perceived impacts of their research. The authors reported that the questionnaire was easy to use and had good internal reliability but only acceptable levels of content validity. Some items, such as those within the categories of social and economic benefits, were judged by experts from different academic disciplines not to reach acceptable levels of content validity. Solans-Domenech et al. (2019) note that the relevance of some items may vary according to the research field of the investigator. A second issue noted by Solans-Domenech et al. (2019) was that their questionnaire relied on the perception and self-reports of the researchers. They suggest that future research with the questionnaire is required, that uses it in the context of a more detailed analysis of the impact of research projects.

In an attempt to address these challenges, the present paper reports on the extent to which a body of research into two screening questionnaires for intellectual disability could be considered to have had an impact, in particular on policy and practice, using the impact questionnaire developed by Solans-Domenech et al. (2019) adapted to the context of intellectual disability services.

This area of research was chosen because the context within which services are delivered to people with an intellectual disability is complex. Here policies and services span health, education and independent sector settings and all age ranges, and must take account of a wide range of stakeholders. Impact can be particularly difficult to assess in such fields due to the complexity of the context in which services are delivered (Scott, Denne and Hastings, 2018). This complexity offered an opportunity both to assess the performance of the impact questionnaire in a context where there are multiple opportunities for different types of impact, but where it may also be more challenging to assess and demonstrate.

The body of research being evaluated for impact relates to two screening questionnaires: the Learning Disability Screening Questionnaire (LDSQ) and the Child and Adolescent Intellectual Disability Screening Questionnaire (CAIDS-Q) for use with adults and children and young people respectively. The development of both was prompted by research that indicated that knowledge about, and recognition of, intellectual disability was often limited, even in professional groups that should be well placed to identify this group of people, such as health, social care and education staff (McKenzie et al., 2000; Rae, McKenzie and Murray 2011).

The delays in identifying that a person has an intellectual disability or the fact that it is overlooked potentially has many negative consequences. For example, early interventions have been shown to improve the functioning of the person (Guralnick, 2017) while ‘reasonable adjustments,’ such as regular health checks result in improved health for people with an intellectual disability (Robertson et al., 2011). Gaining access to this support relies on services knowing that the person has an intellectual disability in the first place, and research by Emerson and Glover (2012), illustrates that the majority of adults with an intellectual disability are ‘hidden’ from services. People with an intellectual disability are also at risk of

being caught up in the criminal justice system and of becoming homeless. In both settings they are vulnerable to exploitation, bullying and abuse (see McKenzie et al., 2012, 2019).

The aims of the development of the LDSQ and CAIDS-Q were to provide evidence-based, quick, easy and accurate measures, that could be used by a range of people to identify whether someone was likely to have an intellectual disability or not. In turn, this would prompt further assessment of those who were identified, providing access to appropriate support as required, whilst reducing the individual and institutional burdens of assessing individuals for whom full assessment is unlikely to be beneficial.

Research into the questionnaires has found them to have strong psychometric properties when used and validated in a range of different settings. These include young offender and adult forensic services (McKenzie et al., 2012, 2012a), homeless services (McKenzie et al., 2019), as well as a range of different health settings including child and adolescent mental health (2012b, 2013), intellectual disability (McKenzie, Sharples and Murray, 2015) and paediatric services (McKenzie et al., 2019a). The diversity of settings in which research into the screening tools has taken place means that the body of research should offer the opportunity to demonstrate impact within many different areas and with many different stakeholders.

The present paper, therefore, aims to evaluate the extent to which:

1. The impact questionnaire developed by Solans-Domenech et al. (2019) can be applied empirically to demonstrate evidence of impact in a complex context;
2. The research underpinning the development of the screening questionnaires achieves impact in the areas highlighted by REF (2019) and operationalised by Solans-Domenech et al. (2019);
3. The application of the impact questionnaire in this context can help inform the wider process of measuring research impact.

Method

In order to find demonstrable evidence of impact, the study comprised two stages. The first involved an online search for published peer reviewed and grey literature and internet resources that referenced the LDSQ and/or CAIDS-Q. The search terms used were the full names and abbreviations of the questionnaires alone and/or in combination with author names and settings in which the measures may have been used e.g., criminal justice, young offender, NHS, health. No date limit was placed on the search. A brief summary was made of the type of evidence found and the website link to it, for all potential sources of evidence of impact. Where possible, sources were downloaded in pdf format. The resultant literature and resources were read in detail to ensure they referred to the correct questionnaires and the details of those that were relevant were recorded separately for inclusion in stage two.

The second stage involved organising the information according to the five main areas of impact outlined by Solans-Domenech et al. (2019) to determine which areas the research had impacted on and to provide supporting examples as evidence. These categories are: knowledge production, capacity building, informing policy and practice, social benefits and economic benefits. Each area has associated sub-sections, for example, 'social benefits' includes benefits to health, quality of life, and safety, among others

The impact questionnaire was designed to be applicable across a range of research disciplines and was found by Solans-Domenech et al. (2019) to have excellent internal consistency as a whole and for all areas, with the exception of economic benefits. Content validity varied across the areas, with agreement on relevance for the greatest number of items being found for knowledge production and the fewest for economic benefits. The authors note that the impact areas may be expected to have different levels of relevance depending on the research

discipline and specific research project, however, it is likely that most researchers would aspire to create impact in as many areas as possible.

With this in mind, an initial process, carried out by the first author, took place whereby it was determined if there was any evidence at all for impact having been demonstrated for each of the categories in the questionnaire, with any relevant sources being assigned to the appropriate sub-category heading. In some cases, the same source provided evidence of impact in more than one category. This process was then refined, with the sources being assigned to the category where they most clearly evidenced impact. At this stage, duplication was minimised, with sources only being assigned to one category as much as possible.

Where there was uncertainty about which category of impact a source of evidence should be placed in, this was discussed with the second and third authors and a decision was made by consensus. For ease of presentation, some items within a category were combined, for example, the different ways of presenting findings, under ‘knowledge production.’

The original questionnaire by Solans-Domenech et al. (2019), required the researcher to respond yes or no to each item, to indicate the perceived presence or absence of a particular type of impact. There was also the option to provide brief information about the type of impact. In the present study, in order to consider a type of impact as present, at least one source of evidence of impact had to be demonstrated. This was to remove the more subjective element of self-report which Solans-Domenech et al. (2019) identified as a potential limitation of their questionnaire, as used in its original format.

2. Results

We present a summary of the areas where the LDSQ and CAIDS-Q research and use could be considered to have had impact, with relevant examples of evidence. This is organised according to the categories outlined by Solans-Domenech et al. (2019).

Knowledge Production

3.1.1 Presenting research findings in abstracts, journal articles, books/book chapters

Twenty-three peer reviewed research articles have been published from the research with authorship including the original developers of the LDSQ and CAIDS-Q (McKenzie, 2012; McKenzie and Megson, 2011; McKenzie and Murray, 2013, 2014; McKenzie, Megson and Paxton, 2008; McKenzie and Paxton, 2006; McKenzie et al., 2012, 2012a, 2012b, 2013, 2013a, 2015, 2019, 2019a, 2019b, 2019c, 2019d; Murray and McKenzie, 2013, 2014, 2014a; Murray et al., 2013, 2015; Paxton et al., 2008). The work has also been referred to in international books by independent authors, with the questionnaires being highlighted as valid screening measures and as providing a way of signposting those who need further assessment (e.g. Bailey, Tarbuck and Chitsabesan 2017; Dom and Moggi, 2014; Lindsay and Taylor, 2018; Mears and Cochran, 2018; Minkoff, 2015; Singh, 2016)

3.1.2 Presenting the research findings in educational materials

The research into the questionnaires has been incorporated into educational materials for a number of audiences, including as part of training workshops for staff using them within criminal justice services (Betts and Gardner, 2009), as part of awareness raising about intellectual disabilities (Cumbria Partnership NHS Foundation Trust, 2015), in a handbook to inform staff working with offenders with an intellectual disability (Department of Health [DoH], 2010, 2011), and as part of NHS Current Awareness bulletins in the UK (e.g. Coventry and Warwickshire Partnership NHS Trust, 2019) and abroad (e.g. Karavalamban, 2016).

3.1.3 Presentations of research findings to the public/patients/end-users

As well as presentations which have included the developers of the LDSQ and CAIDS-Q at conferences and knowledge exchange events (see <https://tinyurl.com/rba5ncu>), there have been a number of presentations and summaries of research findings by independent researchers (e.g. Murphy, 2016, 2018; Hawkins, 2018; Salvesen Mindroom Centre, 2017); highlighting them to clinicians (e.g. Malone and Bain, 2018) and liaison and diversion staff (DoH, 2015).

3.1.4 Mentioned by the media or the subject of a press release/conference

The questionnaires have been highlighted in a range of presentations and promotional materials. The North East and Cumbria Learning Disability Network (2018) impact statement reports that the newly developed website, which is available to families, carers and professionals, will include the CAIDS-Q, in order to tackle inequalities for people with an intellectual disability. Likewise, NHS Lothian (n.d.) promote their funding of a project which uses the LDSQ to help identify people in primary care homeless services who have an intellectual disability. The LDSQ and CAIDS-Q have also been the topic of a number of international conference presentations by independent researchers, clinicians, and others from a wide range of disciplines, including paediatrics (Cherry, 2019), law and mental health (Chaplin and McCarty, 2018) forensic psychiatry (McCarthy, 2018), criminal justice services (Betts and Gardner, 2009) and supporting victims of sexual assault (Higgins et al., 2019; Rodriguez, Majeed-Ariss and White, 2018; Schofield et al., 2018).

3.1.5 Published through social networks, blogging sites

The screening questionnaires have been referred to in discussions on social network sites such as ClinPsych.org.uk, Oxleas NHS Foundation Trust (2018) Adult Learning Disability

Service Blog, Centre for Applied Disability Research (2014), and on Facebook (e.g. Mac Keith Press, 2019) and Twitter sites (e.g. Dan, 2019).

3.2 Capacity Building

3.2.1 Training for PhD/doctoral students, master's degree students and final year undergraduate projects.

These are outlined as separate categories in the original impact questionnaire, but have been combined here, as it is not always clear which level of qualification a piece of work relates to.

The research and use of the LDSQ/CAIDS-Q have been cited as part of, or formed the fundamental basis of, a number of doctoral theses. These have included theses supervised by the developers of the screening questionnaires (e.g. Paxton, 2015; Scotland, 2015) as well as those undertaken at academic institutions in the UK (e.g. Codd, 2018; Grieve, 2016; Palmer, 2015; Smith, 2016) and internationally (Braatveit, 2018; Heru, 2016; Geijsen, 2018; Goodwin, 2015; Verstraten, 2017). There is also evidence of the questionnaires being referenced in the work of masters students (e.g. Abbo, 2017; Daamen, 2015).

3.2.2 New collaborations at national/international levels

New collaborations have been developed via invitations to contribute to a range of government working groups, including the National Patient Safety Advisory Group, DoH Working Group on Offenders with an Intellectual Disability and DoH/Ministry of Justice comprehensive health assessment tool (CHAT) project. Research collaborations have been developed with researchers in the NHS, criminal justice services, other universities, third sector services (e.g. homeless services) and charities (see section 1a for resulting publications).

3.2.3 New academic networks/additional funding to create new research projects/for research group

Funding has been received by the research team for research into the screening questionnaires and their application in practice by NHS Lothian, Edinburgh & Lothians Health Foundation Trust, Salvesen Mindroom Centre, Northumberland, Tyne & Wear NHS Foundation Trust and NHS Borders.

3.2.4 Research or methods used by other researchers in subsequent research

Many studies, published by independent researchers, have cited the research underpinning and/or used the LDSQ and CAIDS-Q as part of their own research. This has included their potential use by nurses (Delahunty, 2017); in homeless services (Stone et al., 2019); in relation to the impact of immigration on mental health (von Werthern et al., 2018); in criminal justice services (Ali and Galloway, 2016; Ali et al., 2016; Board, Ali and Bartlett, 2015; Boer et al., 2016; Chaplin et al., 2017; Courtney and Lascelles, 2010; Ellem and Richards, 2018; Forrester et al., 2017; Geijsen, Kop and de Ruiter 2018; Gudjonsson, Gonzalez and Young 2019; Gulati et al., 2018, 2018a; Kaal, 2010; Kaal, Nijman and Moonen 2015; McCarthy et al., 2015, 2016; McKinnon, Thorp and Grube, 2015; Murphy, Gardner and Freeman 2015; O'Mahony, Smith and Milne, 2011; Poynter, 2011; Sarrett, 2017; Sen et al., 2018; Short et al., 2018; Silva, Gough and Weeks 2015; Wakeling and Ramsay, 2019; Young et al., 2013, 2018); as part of treatment and intervention studies (Idro et al., 2019; Hall et al., 2019); as part of the neuropsychological assessment or screening processes (Aubry and Bourdin, 2018; Bjørgen, Gimse and Søndena. 2016; Doyle and Mattson, 2015; McInnis, Hills and Chapman 2012; Murphy, 2019; Stirk, Field and Black, 2018; Stevanovic et al., 2018); and as a means of better identifying vulnerable individuals who have been victims of sexual assault (Olsen et al., 2017). It is also being used in ongoing research projects e.g. Sexual Assault Referral Centre (n.d.). The methodology used as part of the development of the questionnaires has also been referenced by other researchers (e.g. Park, 2017).

3.2.5 Contribution to the improvement of research infrastructures

The questionnaires have been identified by staff working in health and other services as beneficial for research purposes, with 83% of staff in child services and 66.7% of those in adult services endorsing this (McKenzie et al., 2019b, 2019c). An example of this in practice is the inclusion of information from the CAIDS-Q in the Autism Spectrum Database-UK, a database available to researchers internationally.

3.3 Informing Policy and Practice

There is considerable overlap between the different categories in this section of the questionnaire, with many documents providing evidence of impact in a number of different areas. To avoid undue repetition, not all sources are included under each category.

3.3.1 Informing as evidence in debates, discussions, or consultancies

The research has been used to shape and inform debates and discussions, particularly in relation to healthcare provision and support for people with an intellectual disability in the UK and internationally. This includes their use to collect basic information to help inform need and service provision for people with an intellectual disability (Yorkshire and the Humber NHS, 2010); highlighting that while the questionnaires are being used across a number of criminal justice services, there is a need for heightened awareness to promote more systematic use of it (HM Inspectorate of Probation & HM Inspectorate of Prisons, 2015).

The research underpinning the questionnaires and their effectiveness has also been highlighted in submissions to Government commissions in the UK and abroad, for example by the Prison Reform Trust (2013) to the UK Government Justice Committee and to the Queensland Productivity Commission's Inquiry on Imprisonment and Recidivism (Catalano, 2018). Similarly, the research has been cited as part of NHS consultations on health strategy.

For example, Inclusion London (2016) responded to the recommendations in ‘Women in the Criminal Justice System in London: A Health Strategy’ by highlighting the need for routine assessment to identify vulnerable prisoners to ensure that they receive reasonable adjustments as part of their care. The response refers to the results of the pilot of the LDSQ in prison and the conclusion that it was an effective tool for this purpose. The Faculty of Forensic and Legal Medicine also highlights the LDSQ in their guidance on assessment of people with learning difficulties and disabilities in police custody (Holmes and McKinnon. 2017).

3.3.2 Informing as evidence in the formulation of norms, guidelines, political initiatives or recommendations by government bodies or other regulators

There is a large body of evidence documenting the ways in which the research into, and use of, the LDSQ and CAIDS-Q has been used to support the formulation of guidelines, policies, recommendations and service pathways. A number of Governmental, professional and other bodies report on the piloting (Holder and Lowes, 2013; Ministry of Justice, 2009, 2011; Prison Reform Trust, 2010, 2011) and evaluation of the questionnaires as measures in themselves or as part of the evaluation of broader pilots (e.g. Haines et al., 2012). For example, the LDSQ has been reported by many sources as an effective measure for use in prisons (Inclusion London, 2016; Marriot, 2017; Murphy et al., 2015; Prison Reform Trust 2010a, 2012; Truesdale and Brown, 2017). The questionnaires have also been recommended for use, highlighted as suitable for use or their use identified as an example of good practice by a number of different individuals and groups (e.g. Adroit Economics & Debra Moore Associates, n.d.; see Czabaniuk and Gavin-Allen, 2013; DoH, 2011; Foundation for People with Learning Disabilities, Marriott, 2017; Royal College of Psychiatrists, 2014; The Magistrates Association, 2011; The Royal College of Nursing, 2015; Smith, 2011; Wright,

McActeer and Francis 2015). The questionnaires have subsequently been rolled out in a number of services, including in criminal justice service (e.g. see Perlinski, 2011) and NHS service pathways (e.g. Ridgeway Partnership, 2011).

A similar process has occurred internationally. For example, the NSW Department of Attorney General & Justice (2014) report on the intention to pilot the CAIDS-Q with young offenders in Australia, while the Victorian Auditor-General's Office (2018) note the planned introduction of the CAIDS-Q to help young people with complex needs. Further details of the subsequent adoption of the screening tools in a range of services is outlined in 3.3.4.

3.3.3 Contribution in the design, planning and management of services and priorities

Given the nature of the questionnaires, and their extensive use in public services, there is considerable overlap between this section and 3.3.2 and the information outlined there is equally applicable here.

3.3.4 The implementation, adoption or production of practices within and beyond the professional world

The LDSQ and CAIDS-Q have been implemented in a range of forensic services in the UK and abroad, including to screen for intellectual disability in prison, young offenders, liaison and diversion, and probation services (Anderson and Cairns, 2011; Durcan et al., 2014; Griffiths et al., 2013; NSW Government, 2017; Oakes, 2013; Senate Community Affairs Reference Committee, 2016; Stimpson, 2011). They have also been included as part of the offender pathways of NHS Trusts (e.g. Ashton, Leigh and Wigan Community Healthcare NHS Trust, n.d.; Criminal Justice and Mental Health Steering Group, 2017; Lloyd, 2014; Oxleas NHS Foundation Trust, 2015; Wrightington, Wigan and Leigh NHS Foundation Trust, 2013); and by the police (Khan and Wilson, 2010; Thames Valley Criminal Justice Board, 2014; Wigan Council, 2013). The NHS have also implemented them as a means of

helping to improve the hospital care of those with an intellectual disability (NHS Wales, 2014) and as part of the assessment process to help reduce drug related deaths in vulnerable people (Collective Voice and the NHS Substance Misuse Provider Alliance, 2017).

3.3.5 Influencing the behaviour of professionals or other people

As highlighted in section 3.3.4, the questionnaires have been introduced into many services. As such, they will have influenced the behaviour of a wide range of professionals and other staff groups. In particular, there has been their systematic use in a number of NHS and criminal justice services (Cumbria Partnership NHS Foundation Trust, 2015; Darker, 2018; Giraud-Saunders and Rashed, 2017; HM Chief Inspector of Prisons, 2012; Robotham et al., 2014; Smith, 2010; Stimpson, 2011; Yorkshire & Hunter Improvement Partnership, 2010).

3.3.6 Influencing education systems and curricular assessments

A number of documents report on the provision of training to a wide range of staff in the use of the questionnaires (e.g. Ashton, Leigh and Wigan Community Healthcare NHS Trust, n.d.; Birmingham Community Healthcare, 2016, Cooper, 2011; DoH, 2011; Smith, 2010; Wigan Council, 2013; Yorkshire & Hunter Improvement Partnership, 2010). As noted previously, reference to the questionnaires has also been made in many educational materials and fact sheets. For example, a fact sheet developed by the Foundation for People with Learning Disabilities. (n.d.) highlights the LDSQ as a way of helping identify people who might have an intellectual disability.

3.4 Social Benefits

3.4.1 Improving health

The main aim of the LDSQ and CAIDS-Q is to facilitate the timely identification of intellectual disability in order for people to receive any required support and maximise their

life chances. Over 80% of professionals surveyed and 65% of parents felt that the use of the CAIDS-Q had helped inform the support needs of children, while 62% of parents felt it had resulted in increased support for the child (McKenzie et al., 2019b). Similarly, over 60% of respondents felt the use of the LDSQ helped identify the support needs of the person (McKenzie et al., 2019c).

Many independent organisations also report on the benefits to health that the use of the questionnaires has brought, particularly to those in criminal justice services. In respect of adults, Dearden (2016), in the Annual Report for HMP Brinsford Young Offenders Institution, reports that the results from the LDSQ is shared with relevant others in the prison to make sure the person receives additional support. Likewise, the Learning Disability Partnership Board in Surrey & Surrey Autism Partnership Board (2015) report that the LDSQ is used in all four prisons in the area to help identify those who are likely to have an intellectual disability. Those prisoners are subsequently offered a yearly health check and associated health action plan. Cooper (2011) also highlights the use of the LDSQ in prisons and the process whereby those who are identified as likely to have an intellectual disability are referred to education and health services and staff are advised about their support needs, as well as the information being incorporated into the person's sentencing plans. Oxleas NHS Foundation Trust (2015) note in their Quality Report 2014/2015 that both the LDSQ and CAIDS-Q are used as part of the Mental Health Practitioner assessments and that this has resulted in those with an intellectual disability being identified and supported at an earlier stage. Likewise, Shaw et al., (2014) in the CHAT Manual note that the CAIDS-Q, which they report as having good psychometric properties, is used if a need is identified.

The questionnaires also impact on health in other areas. For example, Collective Voice and the NHS Substance Misuse Provider Alliance (2017) use the LDSQ as one of the assessments to help reduce drug-related deaths in vulnerable people by assessing risk.

3.4.2 Improving quality of life

There is evidence that using the LDSQ and CAIDS-Q impacts positively on quality of life. Over 60% of parents and professional staff agreed that the use of the CAIDS-Q (McKenzie et al., 2019b) and LDSQ (McKenzie et al., 2019c) had helped improve the well-being and life chances of the person with an intellectual disability. Independent researchers report similar affects, with Hoghton Turner and Hall (2012) citing the use of the LDSQ in criminal justice services as part of improving the health and wellbeing of people with an intellectual disability.

3.4.3 Improving social and cultural determinants

Research indicates that the use of the LDSQ and CAIDS-Q helps identify those who are likely to be vulnerable due to having an intellectual disability. This vulnerability may be because of social, environmental, cultural or other factors. These may include the person's needs not being recognised previously due to limited knowledge in key staff groups about intellectual disability, or individuals being caught up systems that are difficult to understand and navigate e.g. homeless services (McKenzie et al., 2019). Research by McKenzie et al. (2019b, 2019c) found that over 90% of staff working in adult services, 100% of staff in child services, and 73% of parents who were surveyed agreed that the screening questionnaires helped to identify potentially vulnerable people. Importantly, the LDSQ and CAIDS-Q were seen as successful at identifying those who were not previously known to have an intellectual disability, with 96% of staff in adult services, 100% of staff in child services and 77% of parents agreeing that they did so. Their use also resulted in benefits for the wider family system of the person with the intellectual disability, with 83, 62 and 32% of staff working in child services, parents, and staff working in adult services respectively agreeing that their use helped inform the support needs of the family.

Similar results have been reported independently. Wollaston and Odunukwe (2012) highlighted that the use of the LDSQ in prisons led to people being identified as having an intellectual disability who had not previously been known to have one and that this had not been picked up by existing screening methods used by the police.

3.4.4 Improving acceptability

Unfortunately having an intellectual disability can be associated with stigma (Paterson, McKenzie and Lindsay, 2011) and a concern is that screening will likewise be stigmatising. Research suggests, however, that using the screening questionnaires can help improve acceptability by increasing awareness of intellectual disability and understanding of the needs of person. Between 77 and 83% of staff and parents agreed that the use of the LDSQ and CAIDS-Q raised awareness of intellectual disability. Only 19% or fewer felt that screening would be stigmatising for the person (McKenzie et al., 2019b, 2019c). Those using homeless services reported that they would want to undergo screening with the LDSQ if they had an unidentified intellectual disability and that any potential stigma could be addressed by ensuring screening was conducted in the context of an existing relationship and in the best interests of the person (McKenzie et al., 2019). Others concur, with the Independent Monitoring Boards (2010) noting, in the HM Prison Full Sutton Annual Report, that the LDSQ addresses the issue of prisoners being too embarrassed to acknowledge and register their difficulties.

3.4.5 Improving accessibility

The LDSQ and CAIDS-Q are screening, rather than diagnostic measures. As such, they aim to help improve access to assessment and support services for people with an intellectual disability, where full assessment can be provided. The need for the provision of further assessment, in the context of using the LDSQ to screen in prisons, is recognised by the DoH

(2010). The role of the questionnaires in helping promote equality of access was acknowledged by the Ministry of Justice (n.d.) under the heading ‘progress toward increased disability equality’ where the results of the LDSQ pilot in prisons are noted.

There is evidence suggesting that the questionnaires have had a positive impact in improving accessibility, for example, facilitating quicker diagnosis in children and young people (McKenzie et al., 2019b) and earlier identification and access to support for offenders (Hawkins, 2018; Oxleas NHS Foundation Trust, 2015). In respect of the latter, Disley et al. (2016) report that, following the use of the LDSQ by Liaison and Diversion staff, the number of appointments for their service users to intellectual disability services increased significantly. Likewise, Birmingham Community Healthcare, (2016) reported that the use of the LDSQ promoted early identification, facilitated referral to intellectual disability services and helped people receive the support they needed at an earlier stage. A similar impact is reported internationally. In Australia, the Senate Community Affairs Reference Committee (2016) notes that all young people who are identified as likely to have an intellectual disability by the CAIDS-Q, as part of the Youth on Track programme receive follow up referral to specialist disability services for assessment. The Cultural & Indigenous Research Centre Australia (2017) also reports using the CAIDS-Q to facilitate referral to clinical services for assessment.

3.4.6 Improving effectiveness or efficiency

Research (McKenzie et al., 2019b, 2019c) has found that 86% of respondents working in adult services, 67% of those working in child services and 58% of parents agreed the questionnaires helped services to prioritise diagnostic assessment. The LDSQ was also seen to assist with reducing waiting times and/or lists for professional services (28%) and lower the time required for assessment (50%). The introduction of the LDSQ has also been used

with the aim of reducing inappropriate referrals to learning disability services (Birmingham Community Healthcare, 2016); improving efficiency by strengthening information and links in relation to the health of offenders in prison (Smith, 2010); gathering basic data about the numbers of prisoners with an intellectual disability (Yorkshire and the Humber NHS, 2010) and informing decisions about the person's pathway through the criminal justice system, at the point of arrest (Prison Reform Trust, 2010b).

The questionnaires are reported as being able to be used by a wide range of people (McKenzie et al., 2019b, 2019c) with minimal demands on those using it and those being screened. Lyon (2010) notes the LDSQ was successfully piloted in prisons and found to be quick and easy to use, requiring minimal training. Similarly, Cooper (2011) reports that the LDSQ provided results that were consistent with those from a more complex measure.

3.4.7 Improving safety

The use of the questionnaires has been highlighted in many NHS Trust quality and performance reports and good practice guidance as outlined in previous sections (e.g. Nottinghamshire Healthcare NHS Trust, 2013). NHS Surrey Public Health Team (2012) report on the introduction of the LDSQ following HMP Downview being rated as red (indicating performance is of serious concern) on indicators in relation to prisoners with an intellectual disability. Likewise, the Prison Reform Trust (2013) cite that the HM Chief Inspector of Prisons had noted the use of LDSQ in some prisons as being indicative of good practice. The DoH (2012) Performance and Quality Indicators of Prison Health cite the use of the LDSQ to identify prisoners with an intellectual disability as one of the green indicators of quality.

3.4.8 Improving well-being and social benefits

As highlighted in a number of previous sections, the use of the questionnaires has resulted in improvements in well-being and social benefits for people with an intellectual disability, their families and staff in many different areas. The details of which will not be repeated again here. The range of benefits are highlighted by Hoghton et al. (2012), who note that the LDSQ is included in the National Offender Management Service (NOMS) draft commissioning intentions for 2013/14 60 with the intention of ensuring there is an effective method for identifying offenders with an intellectual disability. This is in order to make reasonable adjustments and ensure the services meet legal requirements, are decent, and meet the needs of the person appropriately.

3.4.9 Improving competitiveness and development of stimuli

The research resulted in the development of the LDSQ and CAIDS-Q, which, as outlined in previous sections, are extensively used by services in the UK and internationally.

3.5 Economic Benefits

3.5.1 Generating revenue from royalties, equities, industry contracts or any other compensation

The development of the screening questionnaires has resulted in income generation from their use in research and practice.

3.5.2 Leading to the creation of a new business spin-off or start-up company

The publication and distribution of the LDSQ and CAIDS-Q became one aspect of the role of a limited liability partnership.

3.5.3 Bringing innovations, products or devices to market

The research resulted in the development of the two screening questionnaires: the LDSQ for adults and the CAIDS-Q for children and adolescents.

3.5.4 Creation of new jobs

New researcher posts (albeit not permanent posts) have been created as part of grant and project funding relating to the LDSQ and CAIDS-Q. Disley et al. (2016) also note that the restructuring of offender liaison and diversion scheme, of which the LDSQ was used as one of the tools to screen for potential vulnerabilities, led to the development of new support worker jobs.

3.5.5 Bringing wider economic impacts

As was noted in section 3.4.6, the use of the questionnaires was seen by many respondents to increase the efficiency of the service. This is likely to have associated economic benefits. In addition, 36% of staff felt the use of the LDSQ reduced the cost of assessment (McKenzie et al., 2019c). The identification of people whose intellectual disability was previously unknown is also likely to have resulted in wider economic impacts as Barnett and Escobar, (1990) calculate that, based only on financial considerations, the lifetime costs of not identifying someone are greater than overidentifying people.

3. Discussion

The paper had three aims. The first was to evaluate the extent to which the impact questionnaire developed by Solans-Domenech et al. (2019) could be applied to demonstrate evidence of impact in a complex context. We found that it offered a useful and practical framework with which to organise multiple and diverse sources of evidence of impact. While some of the categories had less evidence of impact, none were considered by the research team to be irrelevant. Indeed, using the impact questionnaire helped to highlight those areas where further work might be needed. In our case, the area with least evidence of impact was the economic benefits of the screening questionnaires. While there is some indication of potential economic benefits in terms of increased efficiency of services and the financial

savings of early identification of those with an intellectual disability, using the impact questionnaire indicated that a more robust evaluation, for example, a cost-effectiveness analysis, of this area is required.

The second aim was to use the impact questionnaire to explore the extent to which the research underpinning the development of the LDSQ and CAIDS-Q had resulted in impact in the different categories. The results suggest that the research has had wide-reaching impact in the key areas outlined by Solans-Domenech et al. (2019). The available sources describe a broad process whereby the potential usefulness of the screening questionnaires was recognised by a number of organisations and professional bodies and arguments were put forward in debates, discussions and consultation exercises for their use. This led to the questionnaires being piloted and evaluated in different settings and subsequently being adopted as part of routine systems and pathways of many services in the UK and internationally. While the evidence suggests a general process of policy and professional recommendations leading to implementation and evaluation of the LDSQ and CAIDS-Q, this has not, however, always been in a systematic or comprehensive way. For example, HM Inspectorate of Probation & HM Inspectorate of Prisons (2015) note the need to promote awareness of the screening questionnaires in order to facilitate their use in a more systematic way. Despite this, we found considerable evidence of the positive impact of the questionnaires, recorded in many diverse sources.

In order to maximise dissemination of their results, researchers are encouraged to engage with a range of audiences, using a variety of communication methods, including events such as workshops and seminars, media, social media, academic papers, podcasts, blogs and policy briefs (e.g. Brownson et al., 2018). In the case of the screening questionnaires, it seems likely that their wide-ranging impact was due to a number of factors.

First, the large body of research that underpinned their development provided reassurance that, while only designed to give an indication of likely intellectual disability, they had strong psychometric properties and chances of misclassification were relatively low. Second, as they could be used by a wide range of people and did not need the person to have a particular qualification or training, they could be used in settings where identifying those people with an intellectual disability would otherwise be complex, expensive, and time-consuming, and access to diagnosing professionals would be likely to be limited e.g. within criminal justice and homeless services. Third, the developers of the questionnaires engaged with a wide range of policymakers, clinicians, and other stakeholders as part of the research and implementation process. As clinicians themselves, they had insight into the challenges of identifying and supporting people with an intellectual disability and aimed to design screening questionnaires that minimised these challenges as much as possible. The fact that the LDSQ and CAIDS-Q are used widely, by many different services to screen tens of thousands of people, suggest that these aims have been met, at least to some extent. As yet, the CAIDS-Q is not used routinely in schools and this remains an area where there is significant potential to promote the early identification and support of children and young people with an intellectual disability.

The third aim was to explore the extent to which applying the impact questionnaire in the context of intellectual disability research could help inform the wider process of measuring research impact. A number of issues were highlighted by the process. While the categories identified by Solans-Domenech et al. (2019) were comprehensive and largely relevant to the area of research being examined, the process of demonstrating evidence of impact identified areas of overlap in a number of categories, particularly in relation to ‘informing policy and practice’ and ‘social benefits.’ It was not always apparent which sources of evidence of impact were best placed in which particular category.

The process also highlighted that the categories worked best for our purposes of demonstrating evidence of impact as an evaluative framework, rather than being scored as a questionnaire. For example, if scoring the questionnaire as ‘present’ or ‘absent’ for evidence of impact most categories would have achieved a score for having evidence, despite some having fewer or less obvious sources of evidence than others.

A related issue is that, while the majority of sources were positive about the screening questionnaires, others highlighted limitations, which would not be readily apparent in some cases, if only scoring for impact. For example, there has been a great deal of independent research into, or using, the LDSQ and CAIDS-Q, which is positive in terms of the category ‘capacity building.’ Not all of the authors, however, found the screening questionnaires to be suitable for their particular purpose, for example, Sen et al. (2018) found the LDSQ to be unsuitable for use with their research sample of immigrants who did not have English as their first language. These examples are useful in that they highlight how the impact of the LDSQ and CAIDS-Q can be improved, for example, by the development and validation of alternative-language versions. Using the questionnaire as an evaluative framework allowed these nuances to become more apparent. In this respect, the process we used brought together elements of both case studies and questionnaires. Indeed, in their early work on the ‘Payback Framework’ Hanney and colleagues (1999) identified the benefits of both approaches and later research (Hanney et al., 2017) note the framework can be used in survey format or applied to case studies.

The inclusion of examples of evidence of impact, while addressing some of the potential issues of researcher self-report of impact, outlined by Solans-Domenech et al. (2019), also raised new issues. For example, some of the evidence for impact within particular categories –especially those relating to ‘social benefits’ such as on health and wellbeing – was drawn from studies conducted by the research teams that included the developers of the screening

tool. While this is not a limitation of the evaluation framework, it may be worth incorporating a more formal method of differentiating impact demonstrated by independent sources, from that generated by the team which developed the original research. This may help researchers to better judge the robustness of the impact based on independent sources only. In the present study, the majority of categories had multiple independent examples of impact.

A further issue which the process highlighted was that of judging the actual and comparative extent of impact from different sources of evidence, and within and between different categories of impact. Hanney et al. (1999) highlighted this issue in their early work and used indices such as the level at which the impact occurred in relation to, for example, influencing policy, and the number of individuals who received some benefit from the impact. In some cases, there are reasonably well-established heuristics for judging impact, for example publication citations. In others, the extent of impact can be difficult to quantify, for example, in relation to increased understanding of an individual's support needs. It is even more difficult to judge whether it is more impactful for research to result in, for example, economic than social benefits.

We did not attempt to make these distinctions in the paper, however, these are judgements which, to some extent, REF assessors are being asked to make in relation to impact case studies in the UK. Research in relation to the 2014 REF indicates that decision-making processes about impact case studies were influenced both by subjective opinion and implicit criteria, such as the style, structure and nature of the narrative and that more tangible evidence of impact was favoured over less tangible evidence (see Reichard et al., 2020). This highlights the need for more explicit criteria on which impact should be judged. Hanney et al. (2017) have contributed to this process by outlining some of the factors that researchers themselves considered to be relevant to the level of impact their research had achieved.

A final issue with our particular approach, rather than with the impact questionnaire itself, was that, as the search used internet sources of evidence, there are likely to be areas of impact that were not identified because they are not documented online. For example, over 150 different NHS and other organisations use the LDSQ and CAIDS-Q, but this use and subsequent impact is not documented in a publicly accessible format.

In summary, the results suggest that the screening questionnaire research had significant, largely positive and wide-reaching impact on policy and practice. The impact questionnaire developed by Solans-Domenech et al. (2019) provided the basis for a comprehensive and useful evaluative framework to assess impact and the process of using it highlighted some wider issues to consider when attempting to evaluate impact.

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