Title:

Finding the right assessment measures for young people with ID who display Harmful Sexual Behaviour

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Abstract

Background: Previous studies and national reports have all noted that a significant proportion of the young people who display harmful sexual behaviours have intellectual disabilities. However research on the topic has been scarce. The current paper presents a systematic review of the literature relating to clinical instruments specifically developed or adapted for adolescents with intellectual disabilities who display harmful sexual behaviours. *Method:* An electronic search of databases was completed for published articles in English from the earliest possible date to the end of 2013. *Results:* No published articles met the full search criteria. This confirmed the lack of published clinical measures, apart from two risk assessment instruments. *Conclusions:* Given the lack of measures it is recommended that the focus of future research needs to be on developing or adapting instruments which will offer researchers and clinicians empirical as well as clinical data on this all too often overlooked population of vulnerable youth.

Introduction

The clinical challenge of assessing and treating individuals with intellectual disabilities who engage in sexually abusive or harmful sexual behaviour is well recognized in intellectual disability services (Broxholme & Lindsay 2003; Keeling et al. 2007a,b; Craig et al. 2010; SOTSEC-ID, 2010; Heaton & Murphy 2013). The fact that many of those with intellectual disabilities begin displaying such behaviour in their adolescence (Murphy, pers. comm.) is less well known.

There is also a growing concern about the issue of young people who display harmful sexual behaviours (HSB) in the general population. Within services for adolescents with HSB, it is thought that between 24 and 38% have intellectual disabilities (Vizard et al. 2007; Hackett et al. 2013), which might be considered a concern given that the estimated population prevalence of intellectual disabilities in the general population is around 2% (Emerson et al. 2012). As a cohort, these adolescents with intellectual disabilities and HSB are considered over-represented in samples of referrals to sexual assessment and/or treatment services (Hawkes et al. 1997; O'Callaghan 1998; Almond et al. 2006), in terms of them being both victims and perpetrators (Hackett et al. 2005; Grimshaw 2008), yet at the same time, they seem to be under-represented in the practice literature and research.

Definition of HSB

The working definition of HSB, for the purposes of this study, is adapted from two sources (Rich 2011; NSPCC, 2013b). Sexual behaviours considered harmful in young people are those behaviours (verbal or physical) between two or more persons which are inappropriate given the ages and/or developmental stages of the participants (Rich 2011). Such behaviours and acts can vary in gravity and at one end can include the use of extreme sexual language, whilst at the other end can include penetrative acts (NSPCC, 2013b).

Characteristics

In clinical practice as well as research, adult sex offenders with intellectual disabilities are regarded as a distinct group of offenders (Lindsay 2002). This is reflected by the existence of specialized risk and clinical instruments applied within the cohort. In developing such instruments, often those with intellectual disabilities who display HSB will be distinguished from three groups: those without intellectual disabilities, those with intellectual disabilities but who are non- offenders and those with intellectual disabilities who display other type of offending behaviours. Through such comparisons, data gathered can offer practitioners much needed knowledge on any distinctive characteristics of the group, especially in focusing on features that relate to treatment evaluations.

Where adolescents without intellectual disabilities are concerned, research has found those who do display HSB to be more prone to displaying internalizing problems in comparison with non-HSB adolescents without intellectual disabilities (Van Wijk et al. 2006). It is also common for them to have a history of sexual victimization; exposure to sexual violence, sex or pornography; poor social competence; low self-esteem; anxiety; and atypical sexual interests (Seto & Lalumiere, 2010). Notably, however, previous systematic reviews and meta-analyses find that amongst a variety of

limitations, the most consistent issue across studies regarding adolescents who display HSB is the utilization of unstandardized measures (Van Wijk et al. 2006; Seto & Lalumi`ere, 2010). Hence, the validity and the reliability of the instruments applied across studies varied to a high degree (Van Wijk et al. 2006).

Data on young people without intellectual disabilities who display harmful sexual behaviour identify them as a heterogeneous group (Almond & Giles 2008), but often the children have histories of severe family dysfunction with disruption of attachment bonds, not helped by a general tendency for them to be separated from parents, with placements away from home. At times, their childhood experiences include abuse (either sexual and/or physical), as well as neglect (Kelly 1992; Department of Health 1999).

In exploring the childhood experiences of adult sex offenders with intellectual disabilities, Lindsay et al. (2001) report 38% of the sample experienced their own sexual victimization. At schools, adolescents with intellectual disabilities and HSB often present behavioural problems, accompanied by social isolation or awkwardness, and psychopathology (Thompson & Brown 1997; Lindsay et al. 2001; Veneziano & Veneziano 2002). Furthermore, early case reports note that young people with intellectual disabilities and HSB were often suffering from a range of social and psychological impairments, such as low self-esteem, loneliness, a fear of intimacy and poor social skills (Becker & Abel 1985). In addition to such complexities for those who display HSB, it is also worth noting that children with intellectual disabilities are more likely to experience a greater range of adverse life events than children without intellectual disabilities and that specific adverse events have been associated with greater psychopathology in children with intellectual disabilities (Hatton & Emerson 2004).

Therefore, it appears that the prevalence of own victimization and risk factors which facilitate the intergenerational transmission of violence and abuse might be greater in individuals with intellectual disabilities, specifically those who display HSB (Browne & McManus 2010).

Victims of adolescents with HSB

The research on victims of adolescents with intellectual disabilities who display HSB suggests that they are mostly opportunistically selected (Ryan & Lane 1991) as the offending behaviours seem to be impulsive in nature (Thompson & Brown 1997). The adolescents appear to be indiscriminate when it comes to victim age and sex, and the strategies used in the offending behaviour are often referred to as unsophisticated (Timms & Goreczny 2002). Compared to non-intellectual disability adolescents with HSB, records show those with intellectual disabilities engage in less grooming behaviours of victims, and some of the earliest research found offending against peers to be most common (Gilby et al. 1989; Ryan & Lane 1991). More recently, it was found victims of adolescents with intellectual disabilities and HSB are often younger than the offenders with intellectual disabilities themselves (Fyson 2007b), which may be linked to the offenders' limited ability to interact with age equivalent peers. Furthermore, a selection of studies finds that the prevalence of intra-familial abuse is higher in cases of adolescents with intellectual disabilities who display HSB (Kelly et al. 2002; Fyson 2007b) than in non- intellectual disability adolescents.

Types of offences

Vizard et al. (2007) report that in their sample of 280 non-intellectual disability adolescents with HSB, 93% of the adolescents had committed contact sexual offences, but that was in addition to engaging in non-contact behaviours. Notably, 72% of the offenders had penetrated their victims either vaginally or anally. Overall, reviews of studies suggest that adolescents with intellectual disabilities display a similar range of offence behaviours to young people without intellectual disabilities (Timms & Goreczny 2002), although youth with intellectual disabilities more frequently engage in non-assaultive behaviours and those considered 'nuisance' offences such as exhibitionism, public masturbation and voyeurism (Stermac & Sheridan 1993). However, categories of HSB are not mutually exclusive and many young people, just as adults do, display more than one type of sexual behaviour.

Recent interest in this population

It is clear that there is a paucity of research targeted at young offenders with intellectual disabilities and HSB. A number of UK national reports have resulted in reviews of youth offending services, and this in turn has highlighted the presence of inequalities and inconsistencies in assessment and intervention work with young offenders with intellectual disabilities (Office of the Children's Commissioner, 2011).

The Bradley Report (Bradley 2009) was one of the first to draw attention to the issues experienced by offenders with intellectual disabilities. The report concludes that limited understanding of child and adolescent development and limited recognition, understanding and management of developmental and neurodevelopmental problems means that often the young people and children are identified through their criminality, rather than their needs and vulnerability (Children's Commissioner Report 2011), aspects which should have been recognized beforehand. Specific shortcomings, such as a lack of evidence-based assessments and treatments, have been identified within service providers and in research around younger forensic groups that include children and adolescents (Youth Justice Board 2008, 2014). In response to this, the National Safeguarding Report (Ofsted, 2008) called for improved provisions for such young people. The report specifically noted that the needs of children and young people with intellectual disabilities are neither well identified nor provided for.

Moreover, in terms of sexual offending, the Multi- agency Criminal Justice Joint Inspection Report (2013) noted that despite the fact that children and young people with intellectual disabilities who commit such offences form a small minority of the overall cohort of those who offend, the impact of their actions could be extremely destructive as they often involved other children and young people. The report concludes with a number of recommendations, such as the call for all agencies to actively contribute to assessments that are intended to inform decision making as well as planning for interventions, in order to minimize the risk of recidivism (CJJI 2013).

Research question

Even though assessments are considered a critical component of treatment evaluation, there has been very little focus on the development of a comprehensive assessment approach for adult sex offenders with intellectual disabilities (Keeling et al. 2007a,b), but this is even truer for adolescents, as evident above. Therefore, this study aimed to investigate what clinical assessment instruments, apart from two known risk assessment tools (AIM 2 developed by G-Map, 2012; and MEGA

developed by Miccio-Fonsea & Rasmussen 2009), have been specifically developed or adapted for adolescents with intellectual disabilities who display harmful sexual behaviours. A systematic review was undertaken, given that it is considered a scientific, replicable and transparent approach in evaluating and summarizing research evidence (Denyer & Tranfield 2009). In addition, it allows for any gaps in the published literature to be highlighted.

Method

Search strategy

An electronic search for adapted measures for adolescents with intellectual disabilities who display harmful sexual behaviours was conducted in December 2014, on databases, up to the end of December 2013. Databases included were EBSCOHost, SCOPUS, PubMed, Cochrane, Web of Science and ISI Proceeding and IBSS. A range of search terms for intellectual disabilities and sexual offending was generated by consulting the literature to identify synonyms (see Table 1 for a list of the search terms). To maximize the number of results, an array of terms representing intellectual disabilities were applied. Search terms were combined using Boolean operators (AND, OR) and truncation was indicated by an asterisk (*) to detect words with various endings (for instance, offen* would capture offence, offences, offending, offender). Articles which had the terms in their abstract or title passed the first screening step, if this was at all ambiguous at the time, the inclusion and exclusion criteria were applied to the abstract.

Given the possibility of publication bias, where studies are not published for various reasons including small samples or poor methodology, the authors were keen to consult with experts from the field. Thus, prior to commencing data collection a UK based advisory group was contacted for consultation. The Learning Disability Working Group (LDWG) was set up in 2008 in response to and in recognition of the lack of adapted resources presently available in the UK for children and adolescents with ID who display HSB. The group meets 2- 3 times a year and is made up of health care professionals and academics who work within the fields of service provision, for both ID and non-ID children and adolescents, at community and residential, hospital and national levels. The focus of the group is on reviewing, adapting and researching tools for assessment and outcome evaluations for adolescents with ID who display HSB.

Selection criteria

The selection process used in this review was to consider all abstract and full text, journal articles (in English) that have adapted a measure, instrument or assessment specifically for the purposes of use within an ID adolescent population, where the young person displays HSB. Published clinical trials, case reports, editorials, guidelines and protocols were considered. Unpublished work was excluded from the review, as were books and book chapters as well as non- English language and thesis publications.

Participants

The review focused upon adolescents with ID who display HSB. Adolescents were defined as young people, aged between 12 and 17 years of age. Those with an IQ <70 and problems in adaptive behaviours meet the classification of ID (DSM-V; APA, 2013). However for pragmatic reasons this review included studies where only the average IQ was reported, provided this was <70.

Results

The search found no publications that met the selection criteria. The most frequently counted reason (number 9) for non- inclusion was that the publication fell into a category which did not include 'adolescents, nor adolescents with ID, it was not an HSB specific cohort, and it did not present an adapted measure'. The two next common reasons (number 10 and 5 respectively) were that it was not a publication that considered 'adolescents with ID, HSB, or adaption of measures' and 'it was a non- ID and HSB specific cohort' (see Flowchart. 1). The LDWG was also able to provide valuable input and feedback on the research on the topic, within the UK and it was confirmed that they also did not know of any adapted tools for this population, though some were beginning to be developed (see below for further details).

Sensitivity analysis

Given the results of the systematic review, a sensitivity analysis was undertaken, by expanding the potential pool of the literature by dropping the word 'adapted' from the search strategy. All the other search terms and equating synonyms remained the same, and a new search was conducted on the same databases over the same period. The sensitivity analysis again yielded no results.

Overall findings

No studies were found through the systematic review of published journals despite the two search strategies, one of which was less limiting and had a wider search scope. However, the author is aware of selective grey literature as produced by the LDWG. The collaborative group, engaged in research work within the UK, has supported the adaptation, for adolescents, of three instruments previously used for adults with intellectual disabilities, through two doctoral research projects. One instrument is an adapted measure of sexual knowledge, The Assessment of Sexual Knowledge (ASK by Galea et al. 2004), the second is an adapted instrument measuring the level of cognitive distortions present in young people, the Questionnaire on Attitudes Consistent with Sexual Offending (QACSO by Lindsay et al., 2007), and the third is work on a victim empathy measure, adapted from the Victim Empathy Scale (by Becket & Fisher, 1994). All three of the instruments are still in the early stages of psychometric data collection with adolescents with intellectual disabilities across sites in the UK.

Implications

The lack of published studies is perhaps not a great surprise. Rather, the results of the systematic review support the less stringent findings from the National Safeguarding Report (Ofsted 2008); Criminal Joint Inspection Reports (2013), the Multi-Agency Youth Justice Report (2013), as well as the Research into Practice Report (Hackett et al. 2013).

The large gap in clinical assessment instruments available for the adolescent with intellectual disabilities who displays HSB is evident and in addressing this gap in knowledge, arguably research needs to turn to the evidence base already established in the mainstream offender work. Historically, conventional sex offender interventions and assessments have been mediated by the 'What Works' approach (Day & Howells, 2002; Martinson, 1974; McGuire, 1995). In practice, this has meant that two offender rehabilitation models, the Risk – Need – Responsivity (RNR) model (Andrews et al., 1990) and the Good Lives Model (GLM) (Willis et al., 2013), have been considered at the forefront of clinical intervention work. Arguably, the same methods might be appropriate for

use with adolescent intellectual disability offenders. Both RNR and GLM have become instrumental in guiding service treatment models, for adult and adolescent services, but also they have been influential in assessment planning and development (Ward et al., 2007).

Risk – Need – Responsivity

In short, the Risk – Need - Responsivity model (Andrews et al., 1990) postulates that the principles of risk, need and responsivity (RNR) need to be adhered to in order to reduce recidivism in offenders (Andrews & Bonta, 2010). The risk principle maintains that the intensity of treatment should match the level of risk (for re-offence) of the offender, the needs principle maintains that for interventions to be effective in reducing reoffending behaviour, they must specifically target the problem areas or needs shown to be empirically associated with criminal behaviour, and the responsivity principle highlights the importance of matching treatment modality with offender characteristics (Andrews & Bonta, 2010).

Risk – Need – Responsivity-based assessment approaches have focused on devising instruments which measure three factors, those addressing the risk, needs and responsivity principles (Kraemer et al. 1995; CSOM 2007; Keeling et al. 2007a,b).

The RNR approach has been widespread in the study of adult sexual offenders but the development and adaptations of specialized assessment tools for any adolescents who display HSB have been limited. In many studies, assessments of the factors as above have met the specific needs of the young population by using child-specific measures, but only a very limited number of studies have developed standardized measures (Frey 2010; Hunter 2011). Furthermore, to date, all such developments have focused on a non-intellectual disability offender population.

Good Lives Model

The GLM on the other hand is embedded in positive psychology, is strengths-based and maintains that whilst risk-based models are needed, they are not enough in addressing the needs of sexual offenders (Willis et al., 2013). Rather, they argue, a treatment model needs to foster the development of both internal and external resources for the individual, in addition to promoting goals that reflect personal identity (Ward & Gannon, 2006). The theory asserts that, when working with sex offenders, clinicians need to focus the intervention towards helping individuals attain fixed goods of value and importance (such as good health, social support, etc.), in an adaptive and appropriate way.

With the emergence of this new model, the focus of assessments has shifted from being risk driven to including more strength-based tools (Worling 2013). GLM adherents argue that the extent to which risk- based assessment tools have been used to date for informing both researchers and clinicians is likely to have led both parties to make inaccurate judgments.

Good Lives Model also recognizes the differences between adults and adolescents in terms of assessment models. It calls for a departure from a purely adult- based frameworks and stipulates that adolescents require a different model (Miner 2002; Rasmussen 2004). Adolescents have a different role within families and their wider community (Rich 2003), and they experience great developmental changes (Calder et al. 2001; Rich 2003) and generally have less established sexual preferences, attitudes and interests (Hanson & Morton- Bourgon 2005). It is recognized that the

assessment focus needs to differ from that with adults, according to the needs of the adolescents, and that it will need to be based on the difficulties presented.

Discussion

As is evident from the literature reviewed, adolescents with intellectual disabilities who display HSB, much like their non-intellectual disability peers, are a heterogeneous group. However, in comparison with their non-intellectual disability counterparts adolescents with intellectual disabilities appear to be more opportunistic, and less complex in their offending behaviours (Almond & Giles 2008). They are more likely to have troubled childhood experiences which might include abuse and neglect (Kelly 1992; Department of Health, Social Services and Public Safety 1999). However, apart from some of these outward (environmental) characteristics, clear systematic and offender-specific, as well as reliable, and valid empirical data are absent. A small number of studies have attempted to compare and contrast the intellectual disability and non-intellectual disability adolescents who display HSB, and in general, the only consistencies reported across the studies are their various methodological limitations (Van Wijk et al. 2006). Such limited studies can only produce general commentary and limited inferences on the specific vulnerabilities and any protective factors of the young people with intellectual disabilities. What therefore is necessitated and highlighted by the present results is the need for the development or adaptation of validated instruments and clinical assessment tools.

In addition to the issues relating to appropriate instruments, another significant methodological limitation noted throughout the papers, as is evident in the exclusion criteria of the systematic review, is the inconsistency in the definition of the term learning or intellectual disabilities, an issue that also arises frequently in research relating to adults (Lambrick & Glaser 2004).

Given that much less is known about the validity of risk-based frameworks in the population of intellectual disability adolescent offenders, mindful progress needs to be made in terms of future directions. In the non- intellectual disability populations, a shift, away from a risk-based paradigm, has been made towards a strengths-based approach instead (Ward et al., 2012). It has been justified as a positive ideology with an aim to provide offenders with motivators that focus away from aberrant behaviours (Ward & Stewart, 2003). Therefore, conceivably the development of new instruments for adolescents should follow a similar direction, with a focus on the development of strengths-based assessment tools. It is only through a shared focus that appropriate programme evaluations could take place.

This systematic review has some limitations. It followed a protocol, but it did not include books, book chapters and doctoral theses. However, through access to the LDWG, who are active in a number of network collaborations and projects related to the present topic, across the UK, it was possible to confirm that no other published adaptations were known to exist.

The current paper aims to direct the spotlight onto an area of work that is significantly under-researched. It is hoped that this paper will stimulate new research to fill the vacuum by kick-starting interest and spurring new ventures in adapting or developing tools which will offer us some invaluable information about this vulnerable group of adolescents and, ultimately, assist in assessing treatment effectiveness.

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Table 1

List of search terms

Search Terms	Command	Subcommand	Variations on the search term
A) Cognitive disabil*	**OR**		
			pervasive developmental disord*
			retard*
			special need*
			handicap*
			learning disabil*
B) Development*	**AND**		
			disabil*
		OR	delay*
		OR	disord*
		OR	limitation*
		OR	imapair*
C) Intellect*	**AND**		
			disabil*
		OR	delay*
		OR	disord*
		OR	limitation*
		OR	imapair*
D) Mental*	**AND**		
			disabil*
		OR	delay*
		OR	disord*
		OR	imapair*
		OR	handicap*
		OR	ill*
E) Results from **A**	**OR**		
			B
			C
			D
F) sex*	**AND**		
			offen*
		OR	abus*
		OR	harm*
		OR	problem*
G) adolescent*	**OR**		
			young person
			young adult
			teen*

			youth
			young people
			juvenile
H) adapted	AND		
			measure*
		OR	tool*
		OR	instrument
		OR	assessment
		OR	outcome

Complete Boolean search sequence:

E AND F AND G AND H

Flowchart 1

Records found through database searching