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## Title:

Keep Safe: the development of a manualised group CBT intervention for adolescents with ID who display harmful sexual behaviours

#### **Abstract**

This paper focuses on the development of *Keep Safe*, a manualised group intervention for adolescents with intellectual disabilities who display harmful sexual behaviour (HSB), and is the initial phase of a feasibility study. National reports have highlighted the need for the development of specialist programmes, as adolescents with intellectual disabilities make up a significant proportion of young people referred to specialist HSB services and there is a lack of evidence or practice-based interventions for them. Keep Safe development progressed from the practitioner /researcher collaborative ySOTSEC-ID (young Sex Offender Treatment Services Collaborative- Intellectual Disabilities) through a project team, the Keep Safe Development Group (KSDG), comprising a range of practitioners with a variety of clinical expertise across services, and an Advisory Group of people with ID. Aims included taking account of adolescents' and families' needs, motivations and practical commitments, integrating best- practice and being accessible and appropriate across different types of services. An expert-consensus methodology based on the Delphi method was used. The iterative process for the manual draws on the slim practice-based evidence from United Kingdom, New Zealand, North America and Australia. Keep Safe comprises six modules distributed through 36 term-time young people's sessions, alongside 16 concurrent parental/ carer sessions (some joint). The main focus of Keep Safe is to enhance well-being and reduce harm. Four initial sites volunteered as feasibility leads, and 2 more were added as recruitment was more difficult than foreseen. This study is innovative and valuable given the recognition that research and practice is significantly lacking in this area.

Keywords: CBT, intervention, IDD, adolescents, harmful sexual behaviours.

#### Introduction

Children and young people have been reported to commit up to 30-35% of all known sex offences and it has been found that those with intellectual disabilities (ID) are over-represented amongst these perpetrators (Almond, Canter & Salfati 2006, O'Callaghan 1998, Hawkes, Jenkins & Wizard 1997, Hackett et al. 2013). The exact proportion of the young people who display harmful sexual behaviours

(HSB) and who also have ID is unknown, with studies reporting figures ranging between 4%-40% (Hayes 1991, Veneziano, Veneziano 2002, Gross 1985), though some have proposed figures as high as 44%-80% (Dolan et al. 1996, Epps 1991, Hawkes, Jenkins & Vizard 1997, Boswell, Wedge 2004). The largest UK study, Hackett et al.

(2013), found 38% of the sample of 700 children and young people who had shown HSB had intellectual disabilities.

Extreme variations in prevalence rates are part of a contested discussion, and factors which affect reported rates include methodological limitations of studies (Van den Bogaard et al. 2013), sampling biases, as well as filtering effects (Holland, Clare & Mukhopadhyay 2002), the location of the study sample (such as secure children's homes, hospitals, community, or youth offending institutions) and differences in definitions and measures used (Malovic, Murphy & Coulton 2016).

In the UK, the Youth Justice Board reports (Hackett, Masson & Phillips 2005, Youth Justice Board for England and Wales 2008), the National Safeguarding report (Inspectors 2008), NICE guidance (2016), NSPCC Operational Framework (Hackett, Holmes & Branigan 2016), and Barnardo's Reports (Ghani 2016, Franklin, Raws & Smeaton 2015) all recognise a need for practice guidance and resources, as well as training and supervision, in assessing and treating children and young people with ID who display HSB. The Joint Inspection report (Fox 2013) and a recent Research to Practice Review by Hackett (2014) found access to services, especially for those with ID, to be inadequate, resulting from poor recognition of the offence, lack of care pathways and services (Fox 2013). Specifically these reports found very few examples of interventions and research, both of which are likely to have contributed to the lack of access.

For adult sex offenders, group cognitive behavioural therapy (CBT) is known to be an effective intervention (Aos, Miller & Drake 2006, Kenworthy et al. 2003). One such programme, SOTSEC-ID (Sex Offender Treatment Services Collaborative – Intellectual Disabilities, see <a href="www.kent.ac.uk/tizard/sotsec">www.kent.ac.uk/tizard/sotsec</a>), has been successfully trialled for adult men (18+) with ID and harmful sexual behaviours (Murphy et al. 2007, Murphy et al. 2010). Completion rates were high (over 90%). Following their participation in the adapted programme men's sexual knowledge and victim empathy increased, cognitive distortions reduced and recidivism rates were low (Murphy et al. 2010, Murphy et al. 2007, Heaton & Murphy 2013).

SOTSEC-ID, the collaborative that ran the adult research, recognised that many of the adults in their treatment programme had long histories of harmful sexual behaviours, stretching back into their childhoods/ adolescence. Indeed Vizard et al. (2007) found the average age of onset in a nondisabled cohort of adolescents to be 9.5 years. ySOTSEC-ID also recognised that there was a lack of adapted assessments available (Malovic, Murphy & Coulton 2016), as well as a paucity of intervention programmes and empirical research for children and young people with ID who display harmful sexual behaviour (HSB).

ySOTSEC-ID ('y' for Young) was therefore set up in 2012 as a subgroup of SOTSEC-ID. The objective was to create a platform for clinicians, service providers and academics within the UK to begin to share knowledge and experience of working with children and young people with ID and HSB, and to develop a similar intervention protocol to that which had been already evaluated for adults with ID.

Group CBT appeared promising as an intervention, as it had been evaluated for adults with ID and HSB, as well as having been noted as an effective approach for non-disabled children with problematic sexual behaviour (Carpentier, Silovsky & Chaffin 2006). CBT has also been adapted and used successfully with children and young people with ID and other psychological difficulties, not including harmful sexual behaviour (for example, see (Andrews et al. 2010, Wiggins, Hepburn & Rossiter 2013).

Led by members of ySOTSEC-ID, the current study details how an adapted intervention model and materials were developed for adolescents with ID and HSB with the aim to address the gaps in evidence-based service provision.

#### Methods

The ySOTSEC-ID meetings (n=15), since 2012, enabled the sharing of practice-based frameworks, methods, models and resources already in use in assessment and intervention with children and young people with ID and/or HSB in the UK and internationally. A references and resources list was compiled and posted on the ySOTSEC website (http://www.kent.ac.uk/tizard/sotsec/ySOTSEC/resources.html).

The *Keep Safe* Development Group (KSDG), a small subgroup of practitioners and researchers involved with ySOTSEC-ID, and already with significant expertise in this field, was identified and supported by funds from the Paul Hamlyn Foundation (September 2013-February 2016) and a University PhD Bursary (for AM). The KSDG met with the aims of developing the manualised intervention, *Keep Safe*, and trialling the manual in some initial intervention groups for young people with ID and their carers.

Meeting monthly for the first 6 months, then quarterly, the KSDG comprised six practitioners and researchers based in a range of services (residential, secure and community sites; NHS and charity based services, and a University). Also included was a lead advisor from an Advisory Group for service users/experts by experience. The KSDG members brought with them a variety of applied clinical experience of working with children, adolescents, young adults and adults, with and without ID who display HSB. The focus for the KSDG was to develop a manualised group intervention, accessible across services, taking account of the adolescents' and their families' and carers', needs, as well as their motivations and practical commitments. This was important as very often individuals with ID present with low motivation to make personal changes (Lindsay, 2009). The *Keep Safe* model and manual development progressed through an iterative process drawing on the Delphi Method (Yap et al. 2014, Linstone, Turoff 1975, Langlands et al. 2007, Frankena et al. 2015, Bisson et al. 2010). This used literature searching (for research, practice resources, policy, both formally published and in grey literature), practice-sharing (ySOTSEC-ID, KSDG, other UK and international networking), the mapping and reviewing of

key evidence, models and their elements, integrating, revising, and updating following delivery feedback from feasibility sites (co-facilitators and young people and parent/carer participants), and consideration of emerging evidence to arrive at expert consensus. This also involved sharing between the wider ySOTSEC-ID membership, the KSDG and the *Keep Safe* Advisory Group of members from the ID community meetings.

Final completion of the *Keep Safe* intervention manual, as well as the development of additional guidance for delivering *Keep Safe* as an individually-focused family intervention, where a *Keep Safe* group was not practical or appropriate, has been supported by funding from the Avon and Somerset Police and Crime Commissioner, and the Safer Bristol Partnership to the Be Safe Service, Bristol.

#### <u>Ethics</u>

A favourable ethical opinion was obtained from the Health Research Authority, at the Camden and Kings Cross NRES Committee for a feasibility study of the *Keep Safe* group intervention at four sites, later extended to six sites following recruitment challenges.

## Sites/ services

The six sites in England were a selection of residential and community based NHS and charity services. They were selected as specialist services with a strong interest in developing and/or trialling an ID specific intervention for adolescents who display HSB.

## Training

All feasibility sites were provided with 2 days of training for delivering *Keep Safe* groups including details on the background to the intervention, session content and resources for all modules.

## Policy

The National Institute for Health and Care Excellence, NICE (2016) Public Health Guidance on "Harmful sexual behaviour among children and young people", was being written at the time of the Keep Safe feasibility trials and NICE recognised the need to consider children and young people with intellectual disabilities. This provided an opportunity for one member of

the KSDG to contribute to the guidance. The final guidance (NG55) on "Harmful sexual behaviour among children and young people" can be accessed at <a href="https://www.nice.org.uk/guidance/ng55">https://www.nice.org.uk/guidance/ng55</a>.

#### **Findings**

Keep Safe Group Model and Manual

The final *Keep Safe* group model and manual drew on the slim practice-based evidence available from across United Kingdom (Hackett 2011, Murphy et al 2010, Wiggins, Hepburn & Rossiter 2013), New Zealand (Ayland & West 2006), Australia (Sakdalan & Gupta 2014) and North America (Silovsky et al. 2012, Carpentier, Silovsky & Chaffin 2006). The aim of the model and manual was to maximise its accessibility and acceptability, through young-person-friendly visual, concrete, and creative materials, promoting active learning and roleplay. Developed initially for adolescents with ID who display HSB, between 12-18 years of age, the KSDG consider that this upper age limit could be more fluid, in line with the Children and Families Act 2014 and SEND (Special Educational Needs and Disability) guidance, of supporting young people with SEND until 25 years, dependent on local service provision.

Overall, the iterative *Keep Safe* development process involved sharing between 15 ySOTSEC-ID meetings (March 2012-April 2016), 14 face-to-face meetings of KSDG (September 2013 -February 2016) and 4 tele-conferences (September 2016-March 2017) and 16 meetings of *Keep Safe* Advisory Group of members from the ID community (2014-2015) with feedback from participants and co-facilitators. The sharing of materials, minutes and web-information and training events enabled connection and consultation with the wide network.

The involvement of the *Keep Safe* Advisory Group of service users was key to the development of *Keep Safe*. They met frequently in the early phase giving key advice on both research elements for the feasibility study, such as the information, invitation and consent materials, as well as the *Keep Safe* intervention model resources and materials (see <a href="https://www.kent.ac.uk/tizard/sotsec/KSvideo.html">https://www.kent.ac.uk/tizard/sotsec/KSvideo.html</a> for a short video of their work).

The core elements of Keep Safe include a focus on enhancing well-being (i.e. meeting needs in a prosocial way) and reducing harm (i.e. risk management) of the young people. The programme is primarily based on a modular CBT framework, akin to the adult SOTSEC-ID model, but also incorporating the holistic, and strengths-based Good Lives Model (Ward & Gannon 2006) and the Good Way Model, a programme originating in New Zealand. The Good Lives Model (Willis et al. 2013), suggests that individuals who display HSB do so partly due to a lack of external and internal resources, as well as skills, to help them meet their primary goals by means of prosocial behaviours. It proposes that treatment should focus on fostering the development of these internal and external resources, and that interventions should help individuals attain core personal and social needs, i.e. 'primary goods', in an adaptive and appropriate way (Ward & Gannon 2006). Strength-based, developmental and holistic approaches to harmful sexual behaviour are intended to increase the young person's investment in the intervention process, minimise treatment drop out, and ultimately promote successful completion of treatment. This is important because research has demonstrated that young people who complete interventions for harmful sexual behaviour/sex offending are less likely to reoffend than those who drop out of treatment (Hanson et al. 2002, Hunter Jr & Figueredo 1999, Lösel & Schmucker 2005). Thakker, Ward & Tidmarsh (2006) state that a focus on the acquisition of social skills and a fulfilling and satisfying life will increase the young person's motivation to engage in treatment and enhance the ability of clinicians and young persons to work together, thus strengthening the treatment alliance.

The Good Way Model (Ayland & West 2006, Weedon 2015) is complementary to the Good Lives Model in that it is strengths-based, holistic and contextual. However, it was specifically developed with adolescents with ID who display HSB in New Zealand and has been evolving over nearly 20 years based on engagement with, and feedback from, young people with ID. Group delivery was a substantial element. The Good Way Model is holistic and takes account of social and cultural context, is developmental in approach, addresses trauma, abuse and neglect, and ensures responsibility for any abuse or harm of others remains with the client (drawing on risk-need-responsivity approaches and relapse prevention (Andrews, Bonta & Hoge 1990)). The Good Way Model emphasises client, family and system strengths and uses narratives and externalising. It is now also used with adults with ID and typically

developing children and young people (Ayland & West 2006). The model emphasises that one size does not fit all, interventions must be tailored to the needs of the individual. Work with parents, caregivers and others to develop a more compassionate and understanding view of the client and their experience of trauma and/or their problematic behaviour is key to the Good Way Model and the main elements are:

- A holistic and contextual assessment including the young person and their family's strengths and difficulties
- 'Good Side/Bad Side' one of the basic dualistic concepts, which explores thoughts, beliefs and values through these externalised elements.
- The 'Good Way/ Bad Way', which encourages the person to identify and develop
  a positive lifestyle, by becoming aware of decisions they make about their own
  behaviour (linking to the 'Good Side/Bad Side') and positive and negative
  impulses, cognitions and behaviours.
- The 'Good House/ Bad House', which helps the individuals to explore
  interpersonal experiences, by considering the impact of others' behaviours and
  any feelings of trauma and loss, and exploring issues of belonging, attachment,
  and resilience.
- Making a 'Good Life Plan' summarising the above ideas, with reflection (e.g. 'the sort of guy I used to be', 'what I have learnt', 'what I know now') and consideration of the future ('what I want', 'what I want to avoid').

A significant component of the *Keep Safe* intervention is the involvement of parents/carers. Parents/ carers take part in concurrent sessions, receiving parallel and joint sessions with the young people, to support the young people, sometimes working with parallel material, sometimes on their own issues. This enables the parents/carers to be informed, to develop some understanding of the young person's behaviour, and places them in the best position to support the young people through the treatment process.

Keep Safe session frequency for the adolescents is weekly in term time, with 36 sessions in total. Each session is 2 hours long, split into two halves, with a short refreshment break midway. There are 16 parent/ carer sessions and some are conjointly run with the adolescents. The Keep Safe programme is divided into modules as follows: 1: What Keep Safe is about and getting started; 2: Relationships, sexual relationships and boundaries; 3: Feelings and

managing feelings; **4**: Understanding my behaviour; **5**: Empathy and Consequences (what happens after); **6**: Making my Keep Safe Plan and getting ready to move on

#### **Assessments**

The KSDG also considered appropriate core assessments for this population and agreed a suite of measures. Some of these had already been developed, whereas others were developed specifically for the project. The aims of the assessments were two fold. First, there was a need to establish the young person's cognitive functioning, and their communicative skills, using well-established assessments. Secondly, it was necessary to capture any changes in the HSB young person displayed, their socio- affective well-being, offence specific attitudes, sexual knowledge and resilience. The assessments developed did not include risk assessment procedures as services and sites had their own approaches.

## *Implementation progress*

Despite six sites volunteering to participate in total, only two sites completed Keep *Safe* groups within the funding window, see Table 1. These were two community sites (one NHS, one a national children's charity). 7 participants completed *Keep Safe* groups in this period, 2 participants did not complete the group (1 was withdrawn by parents, 1 Looked After Child was unexpectedly moved to a placement too far away to be able to continue participating).

#### Discussion

A collaborative group of practitioners and researchers used evidence-based-practice, and practice-based-evidence to develop the *Keep Safe* group treatment for young people with ID and HSB. These young people are a vulnerable and marginalised group, as are their families, carers and networks. *Keep Safe* group treatment will hopefully enable adolescents to develop pro-social skills and resilience, safer sexual behaviours and should contribute to harm reduction (reduced numbers of victims and chronicity of harmful sexual behaviour), earlier intervention (few of these young people are currently identified, referred or receive treatment) and reduced health inequalities.

The *Keep Safe* programme is manualised and incorporates considerable parent/ carer involvement. It intertwined features of the Good Way Model and Good Lives Model into the young person and parent/ carer modules, with accessible materials and worksheets provided. The modules have a progressive flow, and are sequenced to introduce substantial concepts such as victim empathy and consequences, in a client focused environment which will feel safe and non-judgmental.

A key element for effective *Keep Safe* delivery is the skills of co-facilitators. Demonstrating empathy and encouragement, being firm but flexible, and creating a cohesive and positive therapeutic climate is more likely to facilitate positive treatment gains and outcomes (see, e.g. Sandhu & Rose 2012, Marshall et al. 2003, Marshall 2005). Therefore, the *Keep Safe* manual has a section on facilitator's group skills, and the sessional activities are designed to provide practice of skills, techniques, and strategies that facilitate the young person's, and their parent/carers' engagement and success in treatment.

The staff at the two sites that ran feasibility Keep Safe groups reported on some initial positive changes clinically observed in the young people and parent/carers who took part. The practitioner feedback included commentary on the positive change in young people's ability to identify emotions, which will aid their emotional regulation. Practitioner feedback also focused on the deliverability of the sessions, the usefulness of the integrated Keep Safe model and materials, and contributed to some improvements for the finalised Keep Safe manual. The data is currently being systematically analysed and will be reported in time. Developing Keep Safe was more time consuming than anticipated and recruiting feasibility sites was much more difficult than expected, given what is known from Hackett et al (2013) and Vizard et al (2007) about the estimated proportion of young people with HSB who also have ID. A number of sites volunteered initially but were then unable to take part due to barriers and recruitment issues as outlined earlier (see Table 1). It seemed likely that the cuts in health and social care funding and staffing were part of the problem. The possibility that austerity has resulted in a larger number of adolescent with HSB and ID being left untreated in the community is a worrying one, where public services may be failing in their safeguarding duties.

As four of the six services hoping to deliver feasibility *Keep Safe* groups were unable to do so in the funding window, additional guidance has been drawn up for delivering *Keep Safe* as an individually-focused family intervention, where a *Keep Safe* group is not practical or appropriate.

#### **Conclusions and Recommendations**

*Keep Safe* was developed as a manualised group intervention for young people (12 years and older) with intellectual disabilities who display harmful sexual behaviour. While recruitment was more difficult than foreseen, sites who delivered *Keep Safe* in the feasibility study gave positive feedback. The study is innovative and valuable given the recognition that research and practice is significantly lacking in this area.

Since, ySOTSEC-ID was formed, and the *Keep Safe* Development Group started its work, there has been more national attention, and policy and practice guidance issued, regarding children and young people who display harmful sexual behaviour and child sexual exploitation, including specific recognition of the vulnerabilities and specific needs of those with intellectual or learning disabilities (NICE guideline 2016, Hackett, Holmes & Branigan 2016, Ghani 2016). *Keep Safe* has the potential to meet some of the unmet needs identified and further practitioner training in *Keep Safe* is planned (<a href="https://www.kent.ac.uk/tizard/sotsec/ySOTSEC/ySOTSEC.html">https://www.kent.ac.uk/tizard/sotsec/ySOTSEC/ySOTSEC.html</a>) which will support practice to grow and allow some shared evaluation as we continue to seek research funding for a systematic and robust evaluation of *Keep Safe*.

Finally, it is important to note that Local Safeguarding Children Boards should use the NSPCC Operational Framework (2016) to ensure they have appropriate provision for children and young people with intellectual disabilities who display harmful sexual behaviour.

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Table 1: Potential sites that agreed to deliver Keep Safe<sup>1</sup>

Site number and type		Recruitment	Trained the team?	Group ran?	Service issues
1.	NHS children's specialist HSB service in SW	Recruited n=5, one pulled out by parents.	Yes	Yes	
2.	City based charity, specialist HSB service	Recruited n=3, one LAC moved placement.	Yes	Yes	
3.	Secure inpatient adolescent LD service, charity (Midlands)	Change in referral flows during the course of the project.	Yes part and other staff experienced in delivering related groups.	No	
4.	Forensic CYP NHS service in NE	Change in referral flows during the course of the project.	Yes	No	Barriers included staff changes and sickness, as well as on-going service reconfigurations.
5.	Town based charity specialist HSB service (SE)	Change in referral flows during the course of the project.	Yes in part, and support available from university based practitioners.	No	Barriers included staff changes, and service reconfigurations.
6.	City based NHS LAC CAMHS (SE)	Insufficient for a group to run	Yes	No	Barriers included geographical spread of LAC population and service reconfigurations.

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<sup>&</sup>lt;sup>1</sup> Note that a number of other possible sites were also approached who eventually decided they would not be able to run the intervention. The six above are those who felt they could definitely run it.