NICE National Institute for Health and Care Excellence

Expert testimony to inform NICE guideline development

Section A: Developer to complete	
Name:	Rowena Rossiter
Role:	Consultant Clinical Psychologist
Institution/Organisation (where applicable): **Contact information:**	Tizard Centre University of Canterbury
Guideline title:	Harmful Sexual Behaviour
Guideline Committee:	Public Health Advisory Committee F
Subject of expert testimony:	Harmful Sexual Behaviour – children and young people with learning difficulties who display harmful sexual behaviour
Evidence gaps or uncertainties:	[Please list the research questions or evidence uncertainties that the testimony should address]

1. Are there specific features relevant to this population group
2. What are the differences between those who have learning difficulties and those with autism
3. What are the similarities and differences compared to those without a learning difficulty and who display harmful sexual behaviour.
4. Is the evidence of effectiveness of interventions for children and young people without learning difficulties directly transferrable to children and young people with learning difficulties.
5. Cross cutting themes that may be relevant to this area and of interest to the committee:
    - Minority populations
    - Young women/gender issues
    - Parents and carers

Section B: Expert to complete

Summary testimony: [Please use the space below to summarise your testimony in 250–1000 words. Continue over page if necessary]

Acknowledgments: Mark Brown, Aida Malovic, Clare Melvin PhD Students and Glynis Murphy, (Tizard Centre and CHSS, University of Kent); Keep Safe Development Group: Stephen Barry, (Be Safe); Emma Marks, (St Andrews); Jack Kennedy, (NTW); Oliver Eastman, (NCATS/Oxleas) plus Aida, Glyn, Rowena; ySOTSEC-ID members, see https://www.kent.ac.uk/tizard/sotsec/ySOTSEC/ySOTSEC.html

Introduction:

Paucity of research (Craig and Hudson,2005; Fyson, 2007; Hackett,2014); gaps reflected in 3 recent PhD searches (AM's systematic review returned no evidence regarding assessments and ID/HSB, CM's systematic review on ASC and offender treatments (including HSB) found only a small number of case series/case studies (echoes Higgs & Carter's, 2015, systematic review on ASC and HSB, CYP/adults)

Effectiveness/cost-effectiveness of different models/tools in assessing the level of seriousness/level of risk posed by, and address the needs of children and young people who display harmful sexual behaviour?

AM's systematic review found no tools that have been psychometrically tested and published in Peer Reviewed journals that are devised for CYP-LD/HSB cohort. Current doctoral projects with adapted knowledge and attitude measures, not complete or published yet. AIM2 found predicted later offending LD (n=46, Griffin & Vettor 2012).

Paucity of research, therefore paucity of evidence….. regarding CYP-LD/ASC who display HSB, gap in anything that would reach the RCT/GRADE standards of NICE.

Scene setting/context: Policy/Legislative/NICE

- Equality/ diversity -all our responsibility, attention to this to reduce health inequalities/inequities; accessible services/reasonable adjustments across protected characteristics (diverse abilities, needs, socioeconomic , culture, age, gender, etc) is a legal requirement (eg Equality Act 2010, NICE)
- Early Intervention/prevention/reduce health inequalities: "proportionate universalism"(CMO Annual Report, 2013, Our Children Deserve Better: Prevention Pays, draw on Marmot, 2013)

Specific features of population group?

Issues

- Definitions/terminology: learning difficulties (20% SEN, education)/learning disabilities (DH impairments in intelligence, IQ>70, and adaptive/social functioning, 2% MLD, less than 1% SLD)/developmental disabilities/neuro-disabilities/neurodevelopmental disorders (ASC/ADHD) etc; inconsistencies/lack of clarity in services/agencies/research overall labels and sub-classifications (mild/moderate etc); diagnostic systems and thresholds;

availability/non-availability of good quality assessments

- Heterogeneous: cognitive wide ranging impairments in intellectual ability, verbal/performance skills, memory, problem solving, executive functioning, communication, physical, social, emotional and self-regulation, sensory abilities; comorbidities (ASC, ADHD, mental health); as ASC is a spectrum- high heterogeneity within this. Implications for assessment and intervention (individually tailored), and for research methodology (within group variance greater than between group, ? more robust single case design see Heyvaert et al.
- Health/social inequalities: higher experience/rates of poverty, bullying, emotional, physical and sexual abuse, mental and physical health, behavioural difficulties and less access to services and support (Foundation for People with Learning Disabilities, 2002; Emerson and Hatton, 2007, Public Health England, 2015)
- Numbers? .. with Complex Learning Difficulties and Disabilities is increasing: Carpenter et al., 2011; Blackburn et al., 2010; DCFS, 2010; http://complexld.ssatrust.org.uk (survival low birth wt babies, FASD, etc); higher rates of learning difficulties/disabilities/neurodevelopmental/communication difficulties are found in "vulnerable" populations (e.g. C&YP in care, EBD/mental health (Emerson & Hatton, 2007) & criminal justice system (Talbot 2007, DH & Bradley 2009a, 2009b, Bryan 2012);
- Frequently go unrecognised in schools, mental health, care, criminal justice settings including services for CYP with HSB: Simonoff et al. 2006, Emerson & Baines 2010; Talbot 2007, Calderbank et al.,2013, Joint Inspectorate Report of n=24 YP/HSB, disability n= 10 (42%), but only 2 had a Statement of Special Educational Needs (8%).
- Denial: "too often subject to disbelief, minimisation and denial by professionals as well as families….. "Calderbank et al. (2013, p8)

Differences between those who have learning difficulties and those with autism?

Learning disabilities- see above

Features of Autistic Spectrum Disorder (ASD)/Condition (ASC):

- a lifelong developmental disability that affects how a person communicates with, and relates to, other people, how a person makes sense of the world around them.
- The three main areas of difficulty, which all people with autism share, are known as the 'triad of impairments':
  1. social communication (e.g. problems using and understanding verbal and non-verbal language, such as gestures, facial expressions and tone of voice)
  2. social interaction (e.g. problems in recognising and understanding other people's feelings and managing their own)
  3. social imagination (e.g. problems in understanding and predicting other people's intentions and behaviour and imagining situations outside their own routine)

Many people with autism may experience some form of sensory sensitivity or under-sensitivity, for example to sounds, touch, tastes, smells, light or colours. People with autism often prefer to have a fixed routine and can find change incredibly difficult to cope with. Some people with autism may have reasonably strong measured IQ, and be severely impaired by features of their autism

Implications: black and white thinking; inflexible thinking; concrete and rule-bound; high anxiety, poor theory of mind, limited empathy, social impairments, unusual sensory interests/dislikes AND…… coexistence of Learning Disabilities & ASC (Turk 2012):

- 70% of children with ASC have a non-verbal IQ below 70
- 50% of children with ASC have a non-verbal IQ below 50
- only 5% of children with ASC have an IQ above 100 (high functioning autism)
- degree of intellectual disability related to likelihood of having ASC & severity of autistic features
- up to 50% of individuals with "severe learning difficulties" have an autistic spectrum condition

Similarities and differences to those without a learning difficulty and who display harmful sexual behaviour?

Similarities

- systemic, safeguarding context (Vizard, 2012)
- strengths based/holistic
- need individualised assessment, formulation and intervention, attention to cultural and gender issues (including diversity of gender and sexuality expression)

Differences

- greater heterogeneity, so assessment, formulation and intervention needs to consider more carefully cognitive ability and social & adaptive functioning, and possible ASC
- Behaviour appears more repetitive and habitual in terms of victim choice, location and frequency.
- May show greater impulsivity.
- May have difficulty understanding abusive nature of behaviour (perspective taking, sequencing).

Evidence of effectiveness of interventions for CYP without learning difficulties directly transferrable to children and young people with learning difficulties? and ASC?

Look to evidence in:

- practice-based evidence with CYP- LD & HSB: O'Callaghan & G-Map (1999, 2004, 2006); Good Way Model, (Ayland and West 2006, Weedon, 2015 n-12, single case design); adapted CBT, (Wiggins et al. 2013), adapted Good Lives Model, (Print et al. 2014, Wylie & Griffin 2013;) practitioner/research networks ySOTSEC-ID, Learning Disability Working Group; use of frameworks- eg Hackett, 2010-continuum, RNR -Risk, Needs, Responsivity, the Draft Operational Framework, 2015
- developmentally younger eg: Group CBT -effective intervention for young children (6-12 years) with problematic sexual behaviour (Carpentier et al 2006). "Turtle programme" - basis for Be Safe, Bristol, Children's Programme (Big Lottery evaluation)
- any LD eg: with adults with LD & HSB, (for the LD adaptations- clear that CYP interventions must be CYP developed) eg effectiveness of SOTSEC-ID,

group adapted CBT, Murphy et al.; Rose et al., Sakdalan, CBT and DBT, 2013) Murphy et al. 2010, 2014

- n=46, ASD diagnoses: 23%; personality disorders 28%; mood disorders 23%; mental illness 9%; offences: stalking, sexual assault, exposure; rape; victims children and adults, male / female; most have long history of similar behaviour (35 with 3 or more such behaviours known), 55% were sexually abused themselves in past.
- Far slower offence disclosure; more on sex education; more pictorial material & less cognitive load/cognitive elements to intervention.
- 6 mths follow-up: 41 men NO further sexually abusive behaviour; 5 men DID show non-contact 'offences' or sexual touch through clothing.
- Re-offending: No relationship with pre- or post- group scores; IQ, presence of mental health problems, personality disorder, living in secure setting, being victim of sexual abuse, history of offending.
- Poorer prognosis: Need for concurrent therapy & diagnosis of ASD
- Now data on n=109, 96% of men who agreed to join research completed ttmt, Process measures: - all $p<0.001$ for changes pre-group to post-group - all $p<0.01$ for changes pre-group to 6 mth follow-up

- any related practice-based evidence with CYP- LD eg: CBT adapted & used successfully in emotions groups (Andrews et al, 2010; Rossiter et al, 2011)

ASC/LD and HSB

- Research finds a proportion of juveniles who sexually offend display autistic traits/have ASC diagnosis (Hart-Kerkhoffs, Vermeiren & Hartman, 2009; Sutton et al., 2013).
- Suggestion that individuals with ASC may be at risk of displaying HSB as a result of associated vulnerability factors, including social naivety, reduced empathy and special interests/'obsession (Dein & Woodbury-Smith, 2010).
- Also, features of ASC may create barriers to interventions for HSB -such as the group setting of typical CBT programmes, inflexible thinking styles and theory of mind difficulties (Howlin, 2004; Dein & Woodbury-Smith, 2010).
- This is yet to be investigated in any controlled or systematic fashion.
- No systematic investigation into the treatment differences between CYP-LD and CYP-ASC who display HSB has been undertaken.
- Above adult -LD research found poorer treatment outcomes for individuals with ASC compared to individuals with LD.
- A small number of case studies have highlighted the complexities of addressing HSB in individuals with ASC, including adolescents, using different approaches (e.g. Griffin-Shelley, 2010; Kohn et al., 1998; Milton et al., 2002).
- Studies specifically investigating the different treatment needs of sexual offenders (either adult or adolescent) with ASC (compared to LD) has not been undertaken, research investigating the efficacy of current adapted sex offender treatment programmes for individuals diagnosed with ASC is yet to be completed.
- Schools and CYP services have identified the lack of available ASC programmes and support services in their areas. Evaluation difficulties arise from lack of appropriate measures to assess impact apart from observing the child's behaviour (MB current

PhD).

Practice-based consensus- interventions need to address:

- shorter attention spans
- more experiential styles of learning
- Careful/matched use of language/communication/cognitive profile (concrete language)
- repetition of messages
- use of visual aids such as story boarding and pictures
- Beware of leading questions, may lead to answers more about pleasing the “adult”, than reality or based on misunderstanding.
- Build skills, confidence, social connections
- High involvement of parent/carers and networks (complex parental needs including poverty, LD)

More research urgently needed-?

Not just specialist interventions at complex end- need stepped matrix strategy approach to prevention CYP-LD and HSB: a comprehensive continuum - prevention to complex intervention (Disability Services, Victoria Department of Human Services 2002)

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