Expert testimony to inform NICE guideline development

**Section A: Developer to complete**

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<tr>
<th>Name:</th>
<th>Peter Clarke</th>
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<tr>
<td>Role:</td>
<td>Director</td>
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<td>Institution/Organisation (where applicable):</td>
<td>Glebe House</td>
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**Contact information:**

**Guideline title:** Harmful Sexual Behaviour

**Guideline Committee:** Public Health Advisory Committee F

**Subject of expert testimony:** Harmful Sexual Behaviour – the development of standardised assessment tools and intervention resources for girls who have engaged in harmful sexual behaviour.

**Evidence gaps or uncertainties:** [Please list the research questions or evidence uncertainties that the testimony should address]

1. The development of the Glebe House model and learning to date.
2. The voice of children and young people as service users.
3. Residential issues relevant to this group of children and young people.
4. Cross cutting themes that may be relevant to this area and of interest to the committee:
   - Minority populations
   - Young women/gender issues
   - Learning difficulties
   - Autism
   - Parents and carers
The Therapeutic Community model is supported by a clear theoretical framework (based on Rapoport’s Four Cornerstones model). Participation and partnership lie at the heart of the interventions. In ‘Unit Ideology’ Rapoport identified four categories that offered a self-definition of the therapeutic community ward he was studying. This concept has been developed at Glebe House to assist the Community’s ability to self-define and our ability to focus efforts on the therapeutic task.

The Cornerstones as they currently stand are:

Democracy – the idea that all Community Members have an expertise to bring to Community decisions. The decision-making process uses consensus rather than voting.

Glebe House is a residential Therapeutic Community specialising in work with older teenagers with a history including sexually harmful behaviour. The service is accredited as a Therapeutic Community by the Royal College of Psychiatry, is a registered Children’s Home (OFSTED) and the treatment of disorder and disease registered with CQC through the pathway of treatment od . It works across a range of ability from mainstream to mild or moderate learning difficulty. Young people may come as an alternative to custody, or post custody or from a non-judicial safeguarding route. Young people are placed for 2-3 years and the majority of the intervention is offered on site by an integrated team of practitioners.

Reality Confrontation – the idea that the Therapeutic Community should remain cognisant of the wider community and prepare members for that world. In addition, the idea that all behaviour has meaning and that all members of the Therapeutic Community have the right to speculate about the meaning of any behaviour within the safety of the daily Community Meetings. These Community Meetings are held three times a day and are Chaired by Resident Chairmen.

Tolerance – previously Permissiveness, this Cornerstone acknowledges that (within reason) there needs to be a culture of tolerating challenging behaviour. If the Community is working to heal severe trauma then there will be times when behaviour becomes challenging. The group’s ability to tolerate these times often has long-term positive effects.
Communalism – the idea that the process of living together as a group managing conflict and establishing boundaries for the group is itself a healing tool.

The work of the Community has been extensively evaluated by an independent 10 year longitudinal research project. This project tracked a ‘completers’ group of over 40 young people for between 2 and 10 years. The research also tracked a sub-group of ‘non-completers’ and significantly a ‘comparison’ group. The comparison group was identified by a paper referral that broke down pre-assessment (usually due to funding issues). This group gives a context to the detailed analysis of the outcomes for the completers group through analysis of Ministry of Justice data. The use of a comparison group is the closest the researchers could manage to a control group. They were matched demographically to the completers group.

The analysis of conviction/reconviction data for the three groups researched reflected established research patterns in that the highest risk group was the non-completers. In addition, the highest risk to all groups was of non-sexual criminal convictions. This has significance in the plotting of future intervention programmes.

When the completers data is looked at with the context of the matched comparison group there is a notable reduction of sexual and non-sexual events. In addition, the severity of the criminal behaviours in the completers group is reduced.

The research highlighted a number of positive outcomes for the completers group that relate to problem solving, quality of life and engagement with local communities. The experience of completing the Glebe House programme has often been carried by those young people into their adulthood. There is a strong sense of the relationships that were formed during those placements creating a positive sense of the potential for future relationships, and a connection to others that had previously not been experienced. These lessons learned mirror the findings of their outcome research projects for this group. Professionals spend a lot of time and energy devising, and debating the best intervention models while service –users remember the relationships and people years after.

The research also highlighted deficits. The three core areas researchers felt needed consideration were:
• Managing long-term transition out of the service. This has been a concern for our service for some time. With the shift in the economic landscape what were patchy services are now even more depleted. This is a great challenge and as a response Glebe House is piloting a Circles of Support and Accountability service (and a parallel 18 month enhanced transitions service). These transition options are free at point of delivery.

• Employment issues for leavers. Youth unemployment is a challenge, care leavers unemployment a greater challenge and employment for young people with a history of sexually harmful behaviour (and potentially convictions and continued state monitoring) makes the situation even bleaker. We have an enhanced education programme to give the best potential available and have started a ‘Social Enterprise’ project (linking with a homelessness charity) as a way of encouraging creative thinking related to employment.

• Consideration for improved access to mental health diagnosis. The traits for a both the completer and non-completer groups includes a significantly high proportion of emerging mental health issues (particularly PTSD and dissociative tendencies). The non-completers were reported with significantly higher prevalence that the completers.

In conclusion the intervention process needs: a strong theory model that can be understood at all levels of the organisation, a stable staff team who are supported, and a commitment to self-evaluation and reflection. Treatment works but also needs to be supported by longer-term support and commitment. We do not expect our own children to be fully independent at 18 or even 25 – why should we expect those with such early year disadvantages to manage without difficulty.
References to other work or publications to support your testimony’ (if applicable):

Re: Research Project Methodology


Re: Glebe House as a Therapeutic Community


Re: Four Cornerstone Model


Re: Outcome Studies


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# Expert testimony to inform NICE guideline development

## Section A: Developer to complete

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<tr>
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<th>Emma Belton</th>
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<td>PHAC F</td>
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**Subject of expert testimony:**

Harmful Sexual Behaviour – Presentation of preliminary results of evaluation study into harmful sexual behaviour

**Evidence gaps or uncertainties:**

[Research questions or evidence uncertainties that the testimony should address are summarised below]
Presentation of results to date on NSPCC evaluation study of harmful sexual behaviour

Cross cutting themes that may be relevant to this area and of interest to the committee:

- Minority populations
- Learning difficulties
- Autism
- 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]

This presentation covers the interim findings from the quantitative evaluation of the NSPCC Turn the Page Service. Turn the Page works with children aged 5 to 18 years with harmful sexual behaviour (HSB). This evaluation focuses on the service offered to young males aged 12-18 years without a learning difficulty. This part of the service uses the Change for Good manual developed by Eamon McCrory (2011).

A qualitative evaluation of the programme has already been published and is available on the NSPCC Impact and Evidence hub. The quantitative evaluation comprises standardised measures administered pre and post programme, matched to the main treatment areas of the manual. A programme integrity checklist is completed by practitioners after each session of the manual to record how the manual has been used. A reconviction study is planned three and five years post programme.

Numbers of completed pre and post standardised measures are quite low due to attrition from both the programme and the evaluation. Data collection will continue until March 2016 to boost the number of completed post programme measures. This presentation is based on interim findings reported in January 2015.

The results showed that there had been improvements on some of the areas covered by the manual, but not all. The appeared to be more change on the areas of the manual covering positive future vision and self-narrative, relationships and managing anger. Progress was more limited for the domains covering healthy vs harmful sexual behaviour, insights of HSB on self and victims, and taking responsibility. There appeared to be less progress on the offence focused measures, particularly for young people involved in...

The programme integrity checklists showed that the material in the manual was viewed as useful, but some improvements could be made. Practitioners felt that it was important to have the flexibility to adapt the material in the manual to meet individual need. It could also take much longer than anticipated to complete the material for each individual session. This led to wide variations in the length of time taken to complete the programme.

The qualitative evaluation showed that many of the young people on the programme...
were facing difficult personal circumstance which could affect their engagement in the programme and the length of time taken to complete the material. Not all young people were getting support from their parents or carers or other professionals and this may lessen any potential impact of the programme.

References to other work or publications to support your testimony' (if applicable):


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# Expert testimony to inform NICE guideline development

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<th>Name:</th>
<th>Rowena Rossiter</th>
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<td>Institution/Org (where applicable):</td>
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<td>Subject of expert testimony:</td>
<td>Harmful Sexual Behaviour – children and young people with learning difficulties who display harmful sexual behaviour</td>
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<td>Evidence gaps or uncertainties:</td>
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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 )

### 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/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;
- Heterogeneity: 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 undersensitivity, 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:

- 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)

References to other work or publications to support your testimony’ (if applicable):


Blackburn C.M., Spencer N.J. & Read J.M. 2010 Prevalence of childhood disability and the characteristics and circumstances of disabled children in the UK. BMC Pediatrics, 10, 21


Carpenter B. 2010 Disadvantaged, deprived and disabled. Special Education, 193, 42-45


Dixon H. 2004 Picture Yourself. CD from www.me-and-us.co.uk


Foundation for People with Learning Disabilities & Mental Health Foundation (2002) Count Us In: Committee of Inquiry into Meeting the Mental Health Needs of Young People with Learning Disabilities . FPLD

Freer, J. http://www.ncbi.nlm.nih.gov/pubmed?term=Freer%20J%5BAuthor%5D&cauthor=true&cauthor_uid=17729143>,


Image in Action Resources: Let’s Do It; Let’s Plan It; The Confidence Factor; Going Further-Getting Started. http://www.imageinaction.org/index.php/resources


Aggression, 14, 135-144
Life Support Productions 2007 Your Body and Sex; www.lifesupportproductions.co.uk/ys.php
McCrorry, E. 2011 A treatment manual for adolescents displaying sexually harmful behaviour: change for good. NSPCC/Jessica Kingsley
NICE, 2008. – Promoting children’s social and emotional well being in primary education
Rossiter et al 2010 Research review - Children and young people with learning disabilities who sexually abuse. Inform, e-journal Community Care, 10 November
Turk J. 2011 Comorbidities: ASD & Other Developmental Disorders. Presentation to ACAMH and BPS/DCP Child and Young Person Faculty LD Network Conference, Leeds
of therapy for young people (with & without an intellectual disability) who have harmful sexual behaviours. DClinPsych. Thesis, Massey University, New Zealand.


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1. The development of the AIM approach and learning to date.

2. Cross cutting themes that may be relevant to this area and of interest to the committee:
   - Minority populations
   - Young women/gender issues
   - Learning difficulties
   - Autism
   - Parents and carers
Title: Building a comprehensive inter-agency assessment and intervention system for children and young people who display Harmful Sexual Behaviours

The issue of children and young people who sexually harm first emerged in the early 1990’s (Ref 1) where it was recognised that multi-agency responses were required but the development of such responses were uncertain and geographically patchy (Ref 2). Remain so to date and the issue is critical in terms of the development of a strategic response. (Ref 3)

Theme: Clear absence of a national strategy for this group:

As a consequence a multi-agency group of experienced managers in Greater Manchester, committed to developing this area of practice established a steering group. As a first step, they commissioned an audit of current working practices across the 10 local authorities to establish assets and gaps and the AIM (Assessment Intervention and Moving on) Project, was established to develop services for children and young people who display harmful sexual behaviours. It recognised that for too long practitioners had been struggling on top of the ‘day job’ to develop appropriate responses for this group.

* A co-ordinator was appointed to;
* Develop inter-agency policies and procedures;
* Local and regional interagency networking and service partnerships;
* Common models of assessment
* Guidelines for schools, residential units and foster carers
* Tool kits for treatment
* External evaluation of both the process and outcomes

Thus form the outset there was a clear vision of strategic partnership objectives that connected to individual agencies, legislative requirements and core business, to more effectively address a child protection issue and enhance existing roles and duties.

Outline of the work of the AIM Project

The AIM Project is not a service provider to which agencies can refer children and young people for assessment and intervention. Focusing responses around a specialist service would not only fail to address the level of demand but also result in unhelpful delays to service provision. The advantage of promoting the involvement of front line agencies directly in the work with this group is earlier recognition, assessment and intervention, thus increasing the chances of prompt engagement. This in turn, is likely to result in a more holistic assessment, reduced denial and the increased possibility of achieving positive outcomes.

Summary of policies and procedures in Greater Manchester and their adaption and adoption to other Local Authorities (Ref 4)
Outline of AIM Project models of assessment and Intervention (Ref 4)

So what does it take to improve practice? Lessons learnt along our way…
*The journey is as important as the destination
*Establish a core and highly committed driver group
*Appoint a ‘change agent’ – co-ordinator to keep the issue ‘live’
*Engage with front line staff
*Integrate new policies and practices within existing bodies of values, knowledge and good practice
*Develop a common model of assessment
*Recognise the importance of a multi-disciplinary training programme
*Engage and equip front line managers
*Use specialist resources strategically
* Plan evaluation from the outset

Conclusion
Locate the understanding of a child/ young person’s sexual behaviour within an ecological view and pay particular attention to their parents and cares (Ref 5)

References to other work or publications to support your testimony’ (if applicable):

2. Exercising constant vigilance… Thematic Inspection 1998
3. Ongoing development work AIM and NSPCC
4. www.aimproject.org.uk
5. AIM2 Assessment model

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