THERAPEUTIC INTERVENTION FOR CHILDREN WITH LEARNING DISABILITIES AFFECTED BY SEXUAL ABUSE

FORMATIVE EVALUATION OF A DEVELOPING SERVICE

Tricia Jessiman and John Carpenter
School for Policy Studies, University of Bristol

December 2018
Impact and Evidence series

This report is part of the NSPCC’s Impact and Evidence series, which presents the findings of the Society’s research into its services and interventions. Many of the reports are produced by the NSPCC’s Evaluation department, but some are written by other organisations commissioned by the Society to carry out research on its behalf. The aim of the series is to contribute to the evidence base of what works in preventing cruelty to children and in reducing the harm it causes when abuse does happen.

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The people pictured are models.
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ACKNOWLEDGMENTS

The authors would like to thank:

• NSPCC children’s services practitioners, team managers and administrators for supporting the evaluation by: explaining the study to children, young people and their families; recruitment; data collection; and management.

• The children, young people and their safe carers who consented to take part in the study and complete evaluation tools.

• The children, young people and their families, as well as NSPCC practitioners and managers, who took part in qualitative interviews.

• David Miller, Emma Belton and Pippa Aspin of the NSPCC for their support throughout the evaluation.

• Dr Sandra Dowling of the School for Policy Studies at Bristol University, for the initial scoping review of the literature that preceded the current study.
1. Introduction

1.1 Children with learning disabilities affected by sexual abuse

Children and young people in England with moderate to severe learning disabilities are around six times more likely to have been affected by sexual abuse than the general population of children and young people (Spencer et al, 2005). There are a number of reasons why this may be so. These children may be particularly vulnerable because they need intimate personal care, which may be provided by multiple carers, outside as well as within their family. They may be cared for away from the family home, in residential care or with foster carers. They may have limited sexual knowledge and lack the ability to interpret social situations, which makes them vulnerable to targeting by sexual predators for grooming and abuse. They may have communication difficulties, low self-esteem and little confidence, making it more difficult to disclose their abuse.

Even if the sexual abuse of children with learning disabilities comes to light, there is evidence from the Children’s Commissioner for England (Horvath et al, 2014) that they may receive a poorer response from professionals than their non-disabled peers. Furthermore, there is little empirical understanding of the effects of sexual abuse on children with learning disabilities and there are no published trials of therapeutic interventions to help these children recover.

A review of clinical studies has suggested that psychodynamic-based interventions that emphasise the value of a close therapeutic relationship and employ creative methods, such as play and painting, may be especially helpful (Allington-Smith et al, 2002). The recent evaluation of a psychodynamic intervention developed by the NSPCC called ‘Letting the Future In’ (Carpenter et al, 2016) showed that this approach can be effective, but it specifically excluded children with learning disabilities. The NSPCC has since adapted it to be suitable for these children and it has now been piloted in four NSPCC service centres. The NSPCC commissioned the University of Bristol to undertake a formative evaluation of the pilot of this adapted version of Letting the Future In (LTFI-LD) to inform the development of the intervention and future roll-out.

This paper begins by describing Letting the Future In (LTFI) and the adapted version for children and young people with learning disabilities (LTFI-LD). It outlines the aims and methods of the study and reports the findings of a scoping review of the literature on the prevalence of sexual abuse and its effects on children with learning disabilities and the effectiveness of existing therapeutic approaches.
The formative process evaluation that follows used interviews and feedback questionnaires to explore the perspectives of NSPCC practitioners and ‘safe’ parents/carers on LTFI-LD. With a view to further summative evaluation, the paper reviews potential outcome measures. It concludes with some recommendations for the roll-out of LTFI-LD.

1.2 Letting the Future In and its adaptation for children and young people with learning disabilities

Letting the Future In (LTFI) is described as a ‘best practice guide’ developed by the NSPCC for therapeutic intervention with children and young people affected by sexual abuse. It is based on a psychodynamic approach, the recovery and regeneration model (Bannister, 2003) and employs creative techniques to develop a therapeutic alliance and support cognitive and emotional exploration and growth. LTFI has been comprehensively evaluated by a team from Bristol and Durham Universities (Carpenter et al, 2016) and is currently being offered by 18 NSPCC teams in England, Wales, Northern Ireland and Jersey. It is also being rolled out to other children’s services through a programme of training and support.

The LTFI practice guide was written for practitioners from a range of disciplines who had previous post-qualifying training and experience in working with children and young people who had been sexually abused. It provides a structured approach to assessment and intervention, together with suggested session plans for therapeutic work. The NSPCC provides an initial training programme and professional development days, plus supervision for children’s services practitioners (CSPs).

LTFI specifically excluded children with learning disabilities but an adapted version of the guide, LTFI-LD, has since been developed (in 2014). This is for use with children and young people with mild or moderate learning difficulties who have been sexually abused; they may also have additional impairments, such as physical and/or sensory impairments, autistic spectrum disorders and mental health needs. In all cases, there must have been either:

- a joint investigation that has concluded sexual abuse has occurred, or
- a multi-agency team of professionals that has concluded there is a strong likelihood that sexual abuse has occurred, but the child has been considered not to have sufficient cognitive ability to sustain an investigation.
In addition:

- The child should be living with a carer who has been assessed as safe and is not living with the alleged perpetrator,

- If in a placement, this has been assessed as stable and there are no planned moves, and significant carer/s are identified to work with the child.

Referrals are taken up to the age of 19; therapeutic work may continue up to the age of 20 and exceptionally longer.

The adapted guide (LTFI-LD) is designed for skilled and knowledgeable practitioners from a range of disciplines working in child sexual abuse who have additional training and/or experience in working with children with learning disabilities. Reflective supervision is an essential component of the work, including assisting practitioners to deal with the emotions involved in helping children affected by sexual abuse.

At the time of this study, LTFI-LD was being piloted in NSPCC teams that already offered the original version of LTFI. The teams were being supported by ‘Respond’, a UK charity working with children and adults with learning disabilities who have experienced abuse or trauma, who contributed to training NSPCC practitioners and provided ongoing telephone consultations as and when required.

The adapted guide is similar in structure and content to the original (see Appendix 1 for details of the original LTFI guide) but has less emphasis on cognitive behavioural therapy (which was thought less likely to be effective) and more reliance on creative therapies, such as artwork, drama, sandplay and therapeutic play. The guide advocates these methods for children and young people who are unable to express their feelings in words because of cognitive impairments or developmental delay. Children’s memories of traumatic experiences may be iconic or sensory rather than in the form of verbal narratives. Creative therapies involve embodiment and projective activities, which can allow children to process their experiences without having to revisit painful experiences that may be retraumatising. Bannister’s Recovery and Regeneration model (Bannister, 2003), which is largely psychodynamic in nature, emphasises the attunement of the practitioner to the child’s affective state. This requires the practitioner first to understand the child’s ways of communicating their feelings and thoughts and to appreciate their level of cognitive functioning, enabling them to build a therapeutic relationship. As Bannister explained, it is the quality of the attachment between child and practitioner and the creativity of the action within sessions that is the core of the model.
The goals of Letting the Future In may additionally include some or all of the following: helping the child to manage their feelings and challenging behaviours; developing coping strategies; recognising inappropriate sexual behaviour by others and protecting themselves from abuse; understanding and stopping their own inappropriate sexualised behaviour; and improving their relationships with parents/carers, siblings, teachers and peers.

The LTFI-LD guide acknowledges that this work may take longer with these children than with their non-disabled peers. Children receive up to six therapeutic assessment sessions followed by up to 30 intervention sessions, and more if required with the approval of the team manager. ‘Safe’ carers are also offered individual sessions with a Children’s Services Practitioner (CSP), the aims of which are to:

- help the safe carer express and process the personal impact of discovering that their child was sexually abused, taking into account their child’s learning disability
- provide socio-educative materials to help them learn about sexual abuse
- help them recognise their child’s needs and think about how they can meet these needs
- assess their suitability and readiness for joint sessions
- complete joint sessions with the safe carer and child or young person, if appropriate, in order to help them communicate about the abuse and to develop their relationship.

Safe carers are offered six to eight sessions with a CSP who is not the same individual working with the child. This CSP may also work with more than one safe carer per case as well as other professionals involved in the child’s care to ensure a consistent socio-educative response.

1.3 Evaluation aims and methods

There is little research into the effects of sexual abuse on children, young people and adults with learning disabilities, and on the efficacy of treatment models. In March 2015, the NSPCC commissioned the University of Bristol to undertake a formative evaluation of the pilot of LTFI-LD as it was being delivered by four NSPCC teams, to inform the ongoing development of the intervention and future roll-out to a greater number of teams.
The aims of the formative evaluation were:

1. To determine whether:
   a. Children and young people experienced the intervention as helpful
   b. Staff considered the approach effective and user friendly
   c. Safe carers reported improved understanding and ability to respond to their sexually abused child

2. To identify barriers and facilitators to the effectiveness of this approach

3. To develop an evaluation design, including the identification of potential process and outcome measures, to inform future testing.

To achieve these aims, the following research activities were undertaken between April 2015 and 2017:

- **A scoping review** of the empirical literature to provide a context for the project and to inform the feasibility and design of any future testing of the intervention using validated and appropriate outcome measures.

- **A formative process evaluation** involving qualitative case studies of the implementation of LTFI-LD in two NSPCC teams, and of six children who received the intervention and the views of their carers.

- A set of paper-based **evaluation tools** to be used with all LTFI-LD cases (with consent).

The full methodology and results of each of these activities is described in detail later in this report. The study design and procedures were approved by the NSPCC’s independent Research Ethics Committee and the Research Ethics Committee of the University of Bristol.

**A note on methods**

The evaluation began in 2015 and was originally intended to include up to 64 children in receipt of the intervention in four NSPCC teams piloting the guide. Following low numbers of children recruited to the intervention, and changes to the teams delivering the guide, the evaluation was paused for 12 months between July 2016–2017. After this date, only two of the original four teams were still delivering LTFI-LD, and the NSPCC indicated plans to identify a further eight teams to deliver the service. In line with this, the evaluation team was asked to deliver evaluation training to these eight teams in addition to the original study; this was undertaken in Oct–Nov 2017.
However, over the course of this evaluation, only two teams had been running LTFL-LD long enough to take part in team case studies, and while it was possible to undertake six family case studies as planned, those were of four families who all received their LTFL-LD from the same team. In addition, the number of paper-based evaluation tools received was very low. Consequently, the findings of the pilot reported here are tentative. It was not feasible to undertake any statistical analysis of paper-based tools so we report descriptive data only. The service will need to be available to greater numbers of children before a summative evaluation of impact is feasible.

For the case studies, we were very mindful of the need to protect the confidentiality of NSPCC practitioners, team managers and service users, all of whom agreed to take part on the basis that they would not be identifiable (including the NSPCC staff themselves). Because of the small numbers of teams, staff and families involved, we have taken steps to ensure this, including not attributing verbatim quotes to individuals, and avoiding the use of any identifiable information.

The methodological tools developed for this study, including topic guides for qualitative interviews and quantitative feedback measures, are published separately.
2. Literature review

2.1 Method

The literature review was undertaken to contextualise the service by answering the following questions:

- What is known about the prevalence of sexual abuse of children with learning disabilities?
- What is known about the specific effects of sexual abuse on children with learning disabilities?
- What is known about the effectiveness of existing therapeutic approaches, and what outcomes might be expected?

And, with a view to a possible summative evaluation:

- What research instruments and measures exist to measure these outcomes that are suitable for use for children and young people with learning disabilities? (The findings on this last question are presented later in the report.)

The following databases were searched for relevant publications: PsychINFO, Web of Science Core Collection, and Ovid. Search terms used included:

- Intellectual disability
- Learning disability
- Learning difficulty
- Developmental disability
- Mental retardation
- Sexual abuse
- Maltreatment
- Abuse
- Trauma

The inclusion criteria applied to the review were that papers should:

- be published in peer-reviewed journals;
- report on original research;
- be directly relevant to individuals with learning disabilities;
- have a particular focus on abuse – specifically in relation to effects, therapeutic approaches and outcome measures);
- be published in English; and

Papers that focused on children aged 18 and under were prioritised, but due to the low number of studies found, the review did not restrict the search to children, as it was likely that studies with adult participants would also prove helpful. For similar reasons, papers that discussed all abuse-related trauma were included (not just
sexual abuse), although sexual abuse was prioritised. After an initial search and screening of abstracts, 176 papers were identified. After full screening, 55 papers were included in the following narrative review, which is presented below in the form of a response to the research questions.

2.2 What is known about the prevalence of sexual abuse of children with learning disabilities?

There is widespread agreement in the literature that the prevalence of sexual abuse among children and young people with learning disabilities is higher than that in the general population of children and young people. A widely-cited US study of over 50,000 children enrolled in schools, including special schools, found that those with an identified disability had a threefold increase in the likelihood of experiencing abuse (not necessarily sexual abuse) (Sullivan & Knutson, 2000). In the UK, Spencer et al (2005) examined data from a whole population birth cohort study (0–19), matching with cases on a county child abuse register. Those children with moderate and severe learning disabilities were almost five times as likely to be on the register for any category of abuse and neglect than non-disabled children. Looking at sexual abuse specifically, the researchers identified a six times greater likelihood. (The register included proven cases of child sexual abuse but also those children at risk because they were living with a known sexual offender.)

An influential systematic review and meta-analysis reported a pooled prevalence estimate for experiencing sexual violence at 13.7 per cent for children with a learning disability (Jones et al, 2012); high rates of sexual abuse are also reported in several other studies (Balogh et al, 2001; Reiter et al, 2007; Jemta L et al, 2008; Fogden et al, 2016).

There may be a number of reasons why children with learning disabilities are at greater risk of sexual abuse. Language impairment may increase vulnerability to sexual abuse because of difficulties in communicating that they have been abused and also because perpetrators may believe that potential victims will be less credible than children who can communicate clearly (Brownlie et al, 2007). Children with learning disabilities may have additional risk factors including having multiple paid and family carers; a need for intimate personal care; low self-esteem; a need to access care away from the family home; limited sexual knowledge and ability to interpret social situations; and poor motor skills that may prevent them fighting off an assault (Crosse et al, 1993; Allington-Smith et al, 2002; Horner-Johnson & Drum, 2006; Briggs, 2006; Akbas et al, 2009; Stalker & McArthur, 2012; Wilczynski & Connolly, 2015; Wissink et al, 2015).
Sexual offenders may take advantage of impairment-related factors to perpetrate abuse. Helton et al (2018) used the three elements of target congruence theory (Finkelhor & Asdigian, 1996) to describe how the personal characteristics of children with learning disabilities make them more vulnerable to sexual offenders’ needs, motives and/or triggers of sexual offences. Children with learning disabilities may experience greater target vulnerability due to having poor communication skills, greater likelihood of misinterpreting social situations, poorer motor skills and/or greater difficulties disclosing abuse. Many children with learning disabilities, unlike those with an obvious physical disability, look like any other child, and may display the traits that a sexual offender may seek (target gratifiability). Finally, children with learning disabilities may be at greater risk of traits that incite anger in offenders, such as poor recognition of social cues and poor communication skills (target antagonism).

Helton and colleagues examined a sample of 2003 child maltreatment investigations across the USA and found support for their proposition. Even when taking into account other factors that increased vulnerability – such as gender, behaviour problems and loneliness – children with learning disabilities were two and a half times more likely to have become the victim of a sexual abuse allegation compared with children without a learning disability. Furthermore, the allegations were much more likely to involve contact sexual abuse, particularly for girls. Helton et al (2018) commented that “…their increased risk of sexual assault further supports a long-recognized characteristic of sexual predators—namely that most do not randomly assault victims but take their time to select vulnerable youth for whom they can manipulate, groom, and ultimately harm.” (p.164). This is a valuable study because it identifies some of the factors that are behind the greater prevalence of sexual abuse of learning-disabled children. The extent to which the same predatory exploitation of these children takes place in the UK deserves investigation. The authors suggested that these children may require tailored prevention efforts to protect them from sexual abuse, which is congruent with the NSPCC adapting the LTFI programme, especially in relation to socio-education for self-protection.

Unfortunately, despite the evidence of higher prevalence of abuse, including sexual abuse, among children with learning disabilities, evidence from the Children’s Commissioner for England (Horvath et al, 2014) suggests that they may receive a poorer response from professionals than their non-disabled peers. Professionals in health, child protection and the police may lack appropriate training and skills to meet the needs of disabled children; be less likely to believe that disabled children have been abused; and have higher thresholds for reporting and registration. Children with disabilities may also be seen as less credible witnesses in the criminal justice system (Stalker et al, 2010; Lainpelto et al, 2016).
2.3 What is known about the specific effects of sexual abuse on children with learning disabilities?

Children with learning disabilities will often have impaired communication and social skills and may also have physical impairments, mental health needs and challenging behaviours. As a result, the children referred to LTFI-LD are likely to exhibit a wide range of intellectual capacities and additional needs. This makes understanding the specific effects of sexual abuse in children with learning disabilities challenging.

In the general population, child sexual abuse is associated with a complex range of psychological symptoms in childhood and adulthood (Berliner & Elliott, 2002; Putnam, 2003), including post-traumatic stress disorder (PTSD), depression, suicide, risky sexual behaviour, sexual abuse perpetration and poor academic achievement (Paolucci et al, 2001). Conversely, several authors in this review lamented the lack of studies of the effects of child sexual abuse (CSA) among children and to a lesser extent, adults, with learning disabilities (Sequeira & Hollins, 2003; Wigham et al, 2011). The limited evidence regarding PTSD, anxiety, depression and behavioural problems is now reviewed.

There is some discrepancy between studies over whether PTSD is a ‘typical’ outcome of abuse for individuals with learning disabilities. Firth and colleagues (2001) examined the effects of sexual abuse among 43 young people with a learning disability (21 victims-only, six perpetrators-only and 16 who were both) and found that only one case met the diagnostic criteria for PTSD. Other studies suggest that PTSD can be one of the effects of CSA for individuals with learning disabilities. Shabalala and Jasson (2011) administered the Child PTSD checklist to 54 young people with a learning disability (half of whom had experienced CSA) and found that there were higher rates of PTSD among the abused group than in the non-abused group. Another study of 256 children who had experienced sexual abuse, 102 of whom had learning disabilities, found no differences in the frequency of post-abuse trauma between children with and without a learning disability. However, those with learning disabilities were more likely to develop some form of conduct disorder (Soylu et al, 2013).

Sequeira and colleagues (2003) conducted a matched-case control study comparing 54 adults with a learning disability who had experienced sexual abuse with 54 adults with a learning disability who had not. The median age of the victim at the time of abuse was 15 years, but the range was wide – from four to 39 – and the median period since the last episode of abuse was three years before
the interviews. The authors concluded that those who had been sexually abused were in general more likely to demonstrate symptoms of PTSD than the non-abused adults. The authors noted that the higher incidence of psychiatric disorder, PTSD, depressive symptoms and anxiety in sexually abused adults with learning disabilities was similar to those reported elsewhere in abused adults without a learning disability. The abused group were also more likely to exhibit some forms of challenging behaviour, including irritability, lethargy, hyperactivity and self-harming behaviours (there was no difference for inappropriate speech). Those who had experienced sexual abuse were also more likely to demonstrate sexualised behaviour and exhibit mental health problems (Sequeira et al, 2003).

Similar findings were reported in a more recent study by Catani and Sossalla (2015) who undertook clinical interviews with 56 adults with learning disabilities who had experienced a range of traumatic life events including CSA, physical and emotional child abuse and family violence and violent attacks in adulthood. CSA was the only significant predictor of the severity of PTSD in adulthood, and was also found to be linked to experiencing intimate partner violence in later life (Catani & Sossalla, 2015). Note that unlike the study by Sequeira and colleagues, there was no comparison group of adults with learning disabilities who had not been abused.

There is some concern, however, over whether current diagnostic criteria for PTSD is fit for purpose for children and adults with learning disabilities, as those with learning disabilities may have responses to trauma that are mediated by their developmental level. It is argued that the general population criteria for PTSD may have to be modified for this group to include behavioural problems, physical health challenges, and changes in skills (Wigham et al, 2011; Rowsell et al, 2013). Mevissen and colleagues (2012), in a review of treatment for PTSD in adults with learning disabilities, noted that symptoms may include acting out traumatic experiences, self-harm, nightmares and trauma-specific re-enactments that, in adults, can appear as symptoms of psychosis (Mevissen et al, 2012). It is also possible that any psychiatric symptoms are wrongly attributed to the learning disability (diagnostic overshadowing) (Mevissen & de Jongh, 2010).

Finally, in the most recent review of the literature on CSA and learning disabilities, Byrne (2017) concluded that there is “no single diagnostic trajectory when dealing with the sequelae of sexual abuse among those with an intellectual disability”. Further, he warned that the presence of psychological symptoms are not in themselves ‘infallible’ indicators of abuse – a more holistic approach to assessment is necessary, including changes in adaptive behaviour and increases in challenging behaviours as well as effects on the wider family.
2.4 What is known about the effectiveness of existing therapeutic approaches, and what outcomes might be experienced?

The paucity of evidence for the effects of sexual abuse for individuals with learning disabilities is mirrored in the lack of studies evaluating treatment options. Empirical research into interventions for the general population of children who have been sexually abused is also relatively under-developed, although a number of randomised controlled trials (RCTs) have been undertaken and discussed in systematic reviews (Ramchandani & Jones, 2003; Macdonald et al, 2012). These studies, almost all of which have been conducted in the USA, provide evidence for the effectiveness of cognitive behaviour therapy. The evaluation of Letting the Future In, which also employed an RCT design, found evidence of effectiveness for the general population of sexually abused children and young people over eight years old over a six-month period, but not for younger children (Carpenter et al, 2016). However, follow-up after one year found that many younger children remaining in the study had recovered. The report noted that LTFI sessions for the young children were spread over a longer period and suggested that cognitive and emotional change may happen more slowly. This may be relevant when considering therapeutic interventions for children and young people with learning disabilities.

We could find no published trial of any intervention for children with learning disabilities who have been sexually abused. This may be for several reasons. Allington-Smith and colleagues (2002) reflected that the diversity of children with learning disabilities in terms of the intellectual impairment, communication skills and additional disabilities means that “no single treatment strategy will be suitable for everyone and this makes it near impossible to have enough young people in a study to yield statistically significant data”. Further, the absence of any standardised instrument to assess the effects of trauma among children with learning disabilities, and hence measure the impact of treatment, contributes to the lack of studies (Sequeira & Hollins, 2003; Mevissen & de Jongh, 2010). It may also be that children with learning disabilities have historically been excluded from psychological interventions because of the belief that they did not have the intellectual capacity or verbal ability to benefit (Sinason, 2002; Cooke & Standen, 2002; Hollins & Sinason, 2000).

Allington-Smith and colleagues’ (2002) paper on therapeutic help for children with learning disabilities who have been sexually abused was based on the clinical experience of a consultant psychiatrist, clinical psychologist and assistant psychologist, all of whom specialised in learning disabilities. Acknowledging the paucity of published evidence, they suggested that psychoanalytical treatment approaches have the following advantages: they may allow children with learning
disabilities to proceed at their own pace; use a range of modes, such as play, art and drama; and if the practitioner is sensitive, enable children with learning disabilities to experience “being truly attended to by an adult that they are unlikely to have experienced before”. This will be especially important for children who have experienced stigma, discrimination and rejection on the grounds of their impairments. Cognitive and behavioural methods may also help children with learning disabilities understand what has happened to them and manage their response to trauma.

The authors noted that regardless of approach, treatment of sexual abuse in this population of children is likely to take longer, will need to use strategies to maximise the communication skills of the child, and address disruptions to attachment to carers, which may follow abuse (Allington-Smith et al, 2002).

The little that is known about interventions for individuals with learning disabilities who have experienced abuse is largely derived from work with adults, rather than children. Promising interventions identified in this review include a survivors’ group with accompanying support group for carers; cognitive behavioural therapy (CBT), and Eye Movement Desensitisation and Reprocessing (EMDR).

First, a small study involving seven adult women with learning disabilities who had been sexually abused aimed to determine the effect of a 20-session survivors group and educational support group for their carers (Peckham et al, 2007). The study found that the women showed increased sexual knowledge, and improvements in both trauma and depression. The significant improvement in trauma was only seen three months after the group had finished, suggesting that more time is needed for people with learning disabilities to reprocess trauma. Challenging behaviours, including self-harm, aggression, rocking and manipulation, got worse during the intervention before they improved.

A review of the evidence on assessment, prevalence and treatment of PTSD in people with learning disabilities (Mevissen & de Jongh, 2010) found that there was little awareness among professionals of the prevalence of PTSD in people with learning disabilities, and of its effects on daily functioning. There is no diagnostic assessment tool for this population, and no empirical studies of pharmacological treatments. The authors found five articles on psychotherapeutic treatment of PTSD in people with learning disabilities. Two discussed the use of CBT; two discussed the use of Eye Movement Desensitisation and Reprocessing (EMDR); and the final paper, psychodynamic psychotherapy. All were used with adults with mild intellectual disability and were case reports of just one to two individuals.
Mevissen and colleagues (2012) described their use of EMDR with two adults and two children with severe learning disabilities and PTSD. Developed by Shapiro, EMDR involves the reprocessing of traumatic memories by asking the individual to bring up the memory, and associated emotions and body disturbance, while tracking the therapist’s moving fingers back and forth with their eyes, keeping their head still (Shapiro, 2001). It is thought that eye movements reduce the vividness and emotional impact of traumatic memories by reducing the capacity of working memory. The approach was adjusted for the two children by asking them to draw a traumatic image, or with another person repeating the traumatic memories aloud. The study found that all four clients experienced a decrease in PTSD symptoms, depressive symptoms and physical distress, and that social and adaptive skills improved (Mevissen et al, 2012). These case studies suggest that an exploratory trial could be worthwhile.

2.5 Summary

Children and young people with learning disabilities are disproportionately susceptible to sexual abuse. There are a number of reasons for this, including the need of many children for intimate care that is often provided by multiple paid carers, often outside the family home. Cognitive impairments may affect their ability to understand appropriate and inappropriate personal, social and sexual behaviours, making them particularly vulnerable to exploitation by sex abusers.

While there is a lack of agreement between research studies on whether or not children with learning disabilities experience the symptoms of post-traumatic stress, the effects of sexual abuse may be evident in behavioural difficulties and emotional problems. The impacts of sexual abuse on adults has been increasingly understood and more sophisticated clinical and empirical methods will likely identify the effects on children more clearly. This would assist the development of the most effective socio-educational and psychological interventions to help children with learning disabilities affected by sexual abuse.

Currently, there is little clinical literature about interventions to help these children and young people and no evidence from experimental or quasi-experimental studies. It has been suggested that psychoanalytically-informed creative therapies may be especially useful, along with cognitive and behavioural approaches. These ideas had informed the development of the adapted model of Letting the Future In for children with learning disabilities.
3. Formative process evaluation

The aims of the process evaluation were:

1. To determine whether:
   a. Children and young people experienced the intervention as helpful
   b. Staff considered the approach effective and user friendly
   c. Safe carers reported improved understanding and ability to respond to their sexually abused child

2. To identify barriers and facilitators to the effectiveness of this approach

3.1 Method

NSPCC team case studies

Qualitative case studies were undertaken between May 2015 and October 2016 with members of two NSPCC teams who had been delivering LTFI-LD for at least six months. The following topics were explored: training and experience of practitioners delivering LTFI-LD; their perceptions of the key features, details and dynamics of the intervention; their opinions about and experiences of using LTFI-LD; experience of delivering LTFI-LD to children with a range of learning disabilities; use of and adaptions to the guide and associated materials; involvement of the safe carer(s) and other professionals in the child’s life; perceived impact on children and their families/caregivers; similarities and differences between the adapted intervention and existing NSPCC approach to working with child sexual abuse (LTFI); and barriers and facilitators to the effectiveness of this approach.

Our original intention was to include three teams, but only two had sufficient experience of delivering the intervention.

In each team, an in-depth interview was held with the team manager and a focus group conducted with children’s services practitioners (CSPs) delivering the intervention. In total, 11 NSPCC staff participated in this element of the study. All were conducted face to face by the lead author. In the first team, five CSPs took part in two focus groups; in the second team, four CSPs took part in a single focus group.
Family case studies

The study also involved qualitative case studies of children and young people who had received the intervention. These allowed children and young people, their safe carer(s) and the professionals delivering the LTFl-LD intervention to contribute to the understanding of the kind of professional practices that are most effective in helping them. In particular, the case studies examined: the acceptability of the intervention to service users and their views of the key elements of the intervention as they experienced it; whether children and their caregivers perceived the intervention as helpful; expected outcomes, and perceived outcomes, for the child and caregivers; use of the guide and associated materials, and amendments required; and, barriers and facilitators to successful implementation.

Case studies of six children, across four families, were undertaken. Within each case study, at least one safe carer and one CSP was interviewed. The practitioner who worked with the child was always interviewed; in two cases the practitioner who worked with the carer was also interviewed. It was our intention to interview all the children, but only one child (and their carer) consented to this. The carer (and child) interviews took place in the family home and CSP interviews at their place of work. In total, 14 people took part in family case studies (details in the table below). Fieldwork was undertaken by the lead author between October 2017 and January 2018.

Table 1. Family case study participants

<table>
<thead>
<tr>
<th>Case Study No.</th>
<th>Child’s age</th>
<th>Gender</th>
<th>Nature of disability</th>
<th>Interviews</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Carer(s)</td>
</tr>
<tr>
<td>1</td>
<td>12</td>
<td>F</td>
<td>Mild to moderate learning disability</td>
<td>Foster carer of 1 and 2</td>
</tr>
<tr>
<td>2</td>
<td>14</td>
<td>F</td>
<td>Mild to moderate learning disability</td>
<td>CSP (child)</td>
</tr>
<tr>
<td>3</td>
<td>18</td>
<td>F</td>
<td>Mild to moderate learning disability</td>
<td>Mother</td>
</tr>
<tr>
<td>4</td>
<td>9</td>
<td>M</td>
<td>Mild to moderate learning disability; Autism</td>
<td>Mother and father</td>
</tr>
<tr>
<td>5</td>
<td>10</td>
<td>M</td>
<td>Mild to moderate learning disability; Autism</td>
<td>CSP (child)</td>
</tr>
<tr>
<td>6</td>
<td>10</td>
<td>F</td>
<td>Mild to moderate learning disability; ADHD</td>
<td>Mother</td>
</tr>
</tbody>
</table>
Qualitative data analysis of case study interviews

All qualitative interviews in both the team and family case studies were digitally recorded and fully transcribed. Following a review of the transcripts, a thematic framework was developed to encompass key themes and sub-themes that emerged from the data and fitted the study objectives. This framework was used to code the data using NVivo software, assigning both verbatim and summarised excerpts of the transcript to one or more theme or sub-theme.

Once all the transcripts were coded and summarised, a detailed and accessible overview of the data populating each theme and sub-theme from every respondent was available. This data management approach facilitates the exploration of the data by both theme and respondent-type, affording the capacity to better describe the data and to explain it through the identification of patterns and associations across and between themes and respondent-types (Miles & Huberman, 1994).

3.2 Findings: Team case studies

Two NSPCC teams participated in the case study interviews: in both cases the LTFI-LD team manager took part in a face-to-face interview, and focus groups were held with CSPs delivering the intervention (nine participants in total across the two teams). All staff interviewed had had experience of using the generic Letting the Future In model for some time; thus, while their experience of the LTFI-LD intervention was more limited, they had extensive experience of delivering a therapeutic intervention to children affected by sexual abuse. At least six of the nine practitioners interviewed had prior experience of working with children with learning disabilities.

Training and supervision

With the exception of one team manager, all staff interviewed had attended two days of training to deliver LTFI-LD run by the NSPCC in partnership with Respond. Views on the usefulness of the training were mixed; several commented on the differences between the two organisations’ ways of working and felt that Respond were likely to be dealing with children with more complex needs and have a longer period in which to deliver therapeutic support. This left some staff (in particular those less experienced in working with children with learning disabilities) feeling daunted by the practice examples used during training and underconfident in their capacity to deliver LTFI-LD. Others, however, felt that the practice examples gave them

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1 Respond is a UK charity that works with children and adults with learning disabilities who have experienced abuse or trauma, as well as those who have abused others, through psychotherapy, advocacy, campaigning and other support. Respond is providing both training and consultancy to NSPCC teams delivering LTFI-LD. www.respond.org.uk/
useful ideas for ways of working, not just with children with learning disabilities, but all children affected by sexual abuse.

All the practitioners said that they would welcome further and ongoing training and support. Topics mentioned included training on specific types of disability, including sensory sensitivity, developmental delay and autistic spectrum disorders. Some CSPs wanted additional resources adapted for children with learning disabilities. However, most also said that they had some success adapting existing resources themselves to suit the needs of the children they were working with – indeed many enjoyed this aspect of the work.

CSPs also have access to telephone consultations with Respond for more challenging cases concerning both children and carers. Staff were positive about the usefulness of these, with one commenting that she “could not continue this work without that support”.

CSPs were happy with the level of individual case supervision and support provided by their team managers but would like more opportunity for joint supervision of CSPs working with the child and the safe carer.

**Working with children with learning disabilities**

All CSPs interviewed had experience of delivering LTFI-LD to at least one child, with some having up to four open cases at the time of interview. All reported that the delivery of the intervention was going well, with children responding to the service positively. CSPs were clear that the key features of the LTFI model are similar regardless of whether a child has a learning disability or not:

> They are children like any other. Once you get children into the playroom they’re children, and that’s the key, isn’t it?

The principle message from respondents was that in the delivery of the intervention for children with learning disabilities, “*everything takes longer*”. This includes building a shared understanding with the child about why they are coming to the sessions; understanding the child’s needs; developing an intervention plan and an approach that would suit the child; building a therapeutic relationship between the CSP and the child; and delivering intervention components and ensuring key messages are understood. The LTFI-LD model accommodates this extended timescale, allocating a greater number of sessions for both therapeutic assessment and intervention delivery than for children on LTFI.
Staff reported that this longer timescale was the most advantageous change to the model and essential for its successful delivery. They also perceived that children with learning disabilities often experienced the external world as fast-paced and complex, and LTFI-LD afforded them a rare opportunity to go at their own pace. In addition, prolonged attention from someone on a one-to-one basis may also be unusual:

Adults might not have taken much notice of what they’re interested in so, maybe for the first time, they’re experiencing acceptance on a different level. I don’t know, that’s just what I’m feeling because some of the children I’m working with have said, “I don’t know, I don’t know,” quite a lot for a long time. It’s like they don’t know anything. So that’s about…maybe not being used to being asked…[]…It can be the first time someone has really shown interest in their thoughts and feelings and they can experience a ‘lightbulb’ moment.

Like the other children receiving LTFI, those with learning disabilities had often experienced trauma for a range of reasons in addition to sexual abuse. Practitioners reported that these children with learning disabilities have often experienced criticism, stigmatisation and bullying on the grounds of their impairments. This increases the complexity of the initial therapeutic assessment:

The young person I’m currently working with, I’m thinking “What are the issues that I’m dealing with? Are they because of your sexual abuse? Are they because of your disability? Are they because you’re being bullied?” And she’s being bullied because she’s got a disability, and they’re all quite linked in.

Practitioners talked about several cases where building trust and engagement at the very start of the service had taken far, far longer than they had anticipated. Examples were shared where children had attended sessions without talking or interacting with the practitioner for weeks on end. This was difficult for CSPs, but staying with the child, accepting silence and non-engagement, but continuing to pay attention and give positive regard to the child for several sessions was necessary to allow them to begin to engage. This required the CSP, and their manager, to persist with the service despite the child’s lack of engagement for some weeks; the flexibility of the LTFI model and the adapted timescales for children with learning disabilities were welcomed. Children with learning disabilities often needed this time to ‘test’ the practitioner and become confident in them:

That challenge, to keep on going. Don’t let go. Just accept him for who he is when he’s there.
The child is thinking “They’re not going away. I’m still here.”

I don’t think anybody had taken the time to work out her communication needs. So, I suppose the assessment being the way it is, and being longer, helps you to be able to work that out.

CSPs also reported frequently spending a long time helping children understand and express feelings and emotions; this tended to be a bigger component of the intervention than for children on LTFI. Staff talked about developing a shared vocabulary and means of discussing emotions as one of the key ‘building blocks’ of the intervention.

While practitioners were at a relatively early stage of implementing this service with children with learning disabilities, they did identify several common factors across cases that were helpful to the work. The use of simple, plain language and being prepared for a lot of repetition emerged as a common theme. CSPs were also clear that finding the best approach to working with the child required a lot of ‘trial and error’; managing failure and staying confident enough to try new things was essential. The expectation that work with children with learning disabilities would require increasingly creative methods in comparison to other children was not always proved correct; practitioners noted that they tended to use a smaller range of activities with individual children. Frequently mentioned methods used to engage children included using printed faces showing different emotions, quiz questions and the use of literal language and lots of repetition.

Despite the challenges, CSPs often reported enjoying the work with children with learning disabilities.

I just love it. It’s another level of complexity, which I really enjoy working with, actually...[ ...I’d love to have a full case load of just learning difficulties if I could.

**Practitioners’ perceptions of the impact on children**

Both the relatively low number of cases and absence of a pre- and post-intervention measure made it difficult for children’s services practitioners (CSPs) to provide evidence of the impact LTFI-LD was having on children who received the intervention. Nevertheless, they were unanimous in their belief that children had benefited. Types of change seen in children included better emotional resilience, improved speech and communication skills, increased confidence, better mood, increased capacity to understand and regulate emotions, and a reduction in nightmares.
Physically, you could see it. Yes. I mean, she’s a cracking kid. She’s amazing. She’s a completely different person now to who I first met...[...] Very shy. Just very closed down in her body language. Like no eye contact. Just staring at the floor and wouldn’t even speak. Now she’s quite confident.

She’s able to advocate for herself a lot more now, which is incredible and [has] improved [her] confidence and self-esteem.

The therapeutic relationship between the CSP and child was seen as the core means through which these improvements are generated. CSPs talked about the importance of making children feel safe, being consistently there for them over time and having fun as core to the process of recovery.

[The] therapeutic relationship, I would say, was massively part of it. Her having fun together, we were able to kind of laugh, and just be together. I think for [child], it was just the boundaries of the therapeutic relationship, and just making sure it was consistent, reliable. Yes, predictable.

**Working with carers of children with learning disabilities**

In many ways, practitioners and their team managers reported more challenges working with safe carers than with the children. Safe carer work had also proved challenging during the evaluation of LTFI, as carers were reported to often be struggling with the impact of discovering their child’s sexual abuse, wider difficulties in family functioning and/or ongoing child protection issues, and/or because the abuse had evoked difficult memories of sexual abuse that carers had experienced themselves. These issues also emerged in the work with carers in LTFI-LD. Again, practitioners reported that it could be difficult for carers to accept the purpose of safe carer work – that the focus is to help the carer meet the needs of the child, not their own needs. CSPs gave several examples where safe carer work had focused on the carer’s own mental health needs for longer than the practitioner would have liked.

Practitioners identified additional reasons why safe carer work could be different from standard LTFI cases that teams had worked with previously. In particular, many carers had often had a “lifetime of battling with services” necessary to meet their child’s needs, especially support in mainstream schools or placement in a special school. They may also have more difficulties arranging replacement care for the child, either informal (family/friends) or paid carers, allowing them to spend time working, socialising or with their other children. These difficulties are exacerbated if the carer has more than one child with
learning disabilities. As a result, carers may be accustomed to being the lead advocate for their child and ‘battling’ with services for adequate provision. This causes them additional stress and anxiety, which also affects family dynamics.

Practitioners reported that encouraging carers to reflect on their child’s needs can be more difficult, as carers understandably feel most expert in the child’s life, and were used to services ‘getting it wrong’:

Challenging yourself as a parent, and as a worker to challenge that in a respectful way...[ ...it’s really offensive if someone says “I think you’re overprotecting”. You think, “I’ve been doing it for years, at home, 24/7, you want to tell me it’s overprotection. Who do you think knows their needs better, me or you?”

In some cases, these struggles with other services were ongoing, and practitioners and managers reported having to spend time supporting carers in their dealings with education and local authority children’s services. Consequently, safe carer work had frequently gone on for longer, and for more sessions, than the guide suggests. Staff reported that initial assessment with the safe carer could take a long time as carers need to explain what has happened to them and their child, and its impact. They may also be the most informative source about the child, including their communication style, trauma-related symptoms and learning disability-related behaviours, and many practitioners valued this time learning about the child from the carer. As a result, one team had changed their approach to initial assessment visits, allocating a worker for the child and the carer immediately, and sending both to the initial meeting with the carer. As a practitioner explained:

...[for] these families and parents...it’s a double trauma; they’ve got the traumatic feelings around having a child with a disability and then the sexual abuse, which magnifies it. They’ve got a lot to tell, and it feels like you need somebody observing and somebody actually having the conversation.

Despite the difficulties, all staff perceived that safe carer work is a key component of the LTFI-LD guide. Practitioners have found it useful in addressing attachment issues that frequently emerge in learning disability cases, in particular encouraging carers to spend quality, one-to-one time with their children. Joint sessions with the child and carer have also been useful in this regard, building communication and helping parents attune to their child’s needs.
Some of it, I have to say, with LD, is family relationships, as well. Some of the attachment isn't as good, I suppose. We've had more joint sessions with some cases on just that – building communication and attunement work with parents and children. The young people will always want more of that.

Other agencies

The LTFI-LD guide recognises the requirement for multi-agency working. This may include the agency that referred the child, and/or local authority children’s services (who will have ongoing responsibilities for looked-after children, or children with a child protection plan). Under Section 17 of the Children Act (1989), all children with disabilities will be defined as ‘children in need’ by children’s services. The child and carer may also be in receipt of services from the education, health and voluntary sectors. The guide states that:

An effective intervention plan needs to occur within a framework of partnership and local networking, together with an expectation that relevant information about the aims of therapeutic intervention and progress at review is shared. Ideally there will be a case management coordinator who will lead on network coordination between the child, the family and the professional network involved.

CSPs and managers considered that the time spent liaising with other agencies over children referred to LTFI is no different for children with learning disabilities than for any child. They give several possible explanations: children referred have tended towards the ‘mild’ or ‘moderate’ end of the learning disability spectrum and do not require (or are not in receipt of) ongoing support from other agencies; ‘austerity measures’ have meant that local authority social work teams are keen to close cases quickly, and also that services in both Child and Adolescent Mental Health Services (CAMHS) and educational psychology have been cut. One respondent noted that they had been “trying to reach out to people who just don’t exist anymore”. Indeed, several staff reported frustration about the lack of provision in education, social services and health services to meet the needs of children with learning disabilities and their families. Furthermore, there was a perception that despite the rhetoric about joined-up and multi-agency working, services for children with learning disabilities are often still very fragmented.
Practitioners were also regularly having to consider how the carers are likely to respond to therapeutic intervention if, at the same time, they are also engaged in disputes with other services for the child. Examples emerged in these interviews (and in family case study interviews) where CSPs had spent a lot of time trying to engage with other agencies to ensure adequate support for a child. This included raising child protection and safeguarding concerns, which were not always immediately recognised by social work teams. CSPs and managers reported difficulties negotiating divergent views between agencies, advocating for the child and, at the same time, delivering a therapeutic service to the child.

Staff also had mixed reports on work with schools. At times, schools have been a rich resource of information about a child’s additional needs and behaviours. They may also be responsive to NSPCC intervention, advise on how best to meet the child’s needs and, in general, be supportive of the therapeutic intervention for the child. However, schools are often a key battleground for families of children with learning disabilities, and both teams had examples where carers were in dispute with schools about the lack of support available for their child. In one case, a child was withdrawn from the LTFI-LD service until an ongoing conflict with education was resolved, as it was felt that the family could not cope with the therapeutic intervention while the child’s educational needs were not being met.

Where children are placed with foster carers, they may have a wider network of support around them to help address any challenging behaviours the child may be exhibiting. Staff noted the need to ensure that the advice and support given to foster carers was aligned with this wider support network.

3.3 Findings: Family case studies

Case studies were undertaken with six children who had completed LTFI-LD, across four families. Interviews were undertaken with five carers, one young person, six CSPs who had worked with the child, and two CSPs who had worked with a carer (14 interviews in total).

Carers’ perception of the intervention with the child

All five carers interviewed were pleased that their child (or children) had been referred to the NSPCC and, in many cases, relieved that they would receive therapeutic help. None reported any concerns. One family would have liked a second sibling to also be accepted onto LTFI-LD at the same time but had to wait until the child had made a clear disclosure.
At the time of the referral, carers had a range of worries about their children. These included challenging behaviours, such as violent outbursts and anger, age-inappropriate sexualised behaviour and potentially harmful sexual behaviour, enuresis and encopresis. Some children had confused and mixed feelings about the alleged perpetrator, expressing guilt and sorrow that there had been no further contact post-disclosure. Several carers were concerned that the child remained especially vulnerable to further sexual abuse and wanted the intervention to address this. Carers, like CSPs, were not always clear how much of these concerns could be attributed to sexual abuse and/or learning disability.

All carers were able to identify aspects of the intervention that they, or their child, had found helpful. NSPCC staff were praised for their flexible and adaptive approach to delivery of the intervention, particularly around the timing and location of sessions. For carers supporting multiple children with learning disabilities and/or dealing with their own learning disability or mental health concerns, this was crucial. Examples of adapting to family circumstances included: the use of volunteer drivers to transport children to the service centre; arranging simultaneous sibling sessions; and arranging carer sessions to meet the individual needs of the carer (including in the carer’s home, or simultaneously with the child’s session). Carers were especially appreciative, pointing out that their experiences of other services for the children had generally been more rigid and inflexible; the NSPCC’s approach gave them confidence that the CSPs understood the challenges of caring for children with learning disabilities.

Most carers also valued the relationship that their child had built with their CSP and were pleased that this afforded the child an opportunity to open up and talk about the abuse. For some respondents, the strength of this relationship exceeded their expectations:

> Just the fact that [CSP] would say that she was getting a lot more from [child] than I expected [child] to give. I thought then, “Well, if [child] feels safe to open up, that’s got to be good. It doesn’t matter if it’s me or [CSP]. It’s got to be good.”

Some carers noted that their children’s challenging behaviours got worse after starting the intervention. Examples included increased incidence of nightmares and disrupted sleep patterns, and worsening enuresis and encopresis. Carers worked with CSPs to develop strategies for coping with this and, while it could be difficult, persevered with the programme. In most cases, these behaviours receded after several months.
All carers recognised and respected the need to maintain confidentiality with respect to the child’s sessions, and for most this was unproblematic. However, tension could arise with the need to feedback progress to carers. For example, in one family the carers would have welcomed more feedback from CSPs about how much (and how) the child was engaging and interacting with the CSP during the early stages of LTFI. These carers would have welcomed the opportunity to advise the CSP on strategies and tools that may have helped the child communicate more easily, and more quickly.

Carers felt supported by their child’s CSP. In some cases, they would contact the CSP between sessions if they had concerns about the child, they attended regular review or joint sessions, and talked with the CSP when dropping off or collecting the child. In almost all cases, the child’s CSP had also advocated with other agencies to help improve the service received. Carers were hugely appreciative of this type of intervention:

Yes, that was really useful. I felt like it wasn’t just me against the school, almost. There was just someone else there. They could ask more questions, as such, in a kind of professional way. Like, if the school said, “We’re going to do this with [child]”, [CSP] was quite good at getting them to elaborate on what that actually meant.

Some carers occasionally found it difficult to assimilate the advice they were being given from different agencies. This was especially true for the foster carer in the sample, who was also being supported by the local authority children’s social care team:

Back then, it was really helpful, but I think we had too many people at that point from too many different organisations, because each would give different coping strategies. We were getting advice from [social worker, three CSPs, independent counsellor, and children’s social care team]. But everyone around us has been really, really helpful.

One carer suggested that a care coordinator would be a solution to this problem:

We just feel like we’d love the equivalent of a McMillan nurse for cancer. So, we’d love somebody who came in and looked at us holistically and said, “What does this family need?” You sort of expect that to be your social worker, and you expect that, hopefully, with the NSPCC, and perhaps that didn’t quite happen how we expected. We feel that we have been left to
negotiate the sea, the fallout. The messages from different agencies about what we ought to be doing with our children. Where they sometimes conflict with either what we can manage in reality, what can be paid for in reality, what can be physically managed, or what, idealistically, we would like as parents is not necessarily considered.

For one family, the relationship between local authority children’s services and the NSPCC was frustrating. Although referred to LTFI-LD by children’s services, the social workers were initially slow to respond when the NSPCC raised concerns about support for the family. The carers reported feeling ‘offloaded’ by children’s services, who advised that the NSPCC was a trusted agency who would best address the child’s needs. At the same time, children’s services were reportedly unwilling to listen to the NSPCC’s concerns:

There wasn’t a sense of parity [between the NSPCC and children’s services]. With the exception of when we were at the child protection panel meetings, there is no hint of parity being considered. You know, this is the opinion of the NSPCC, it’s treated as, “Oh, it’s just another opinion.” Actually, no. You, social services, have handed this function off to another agency who are doing it, effectively, on your behalf.

Perceptions of the impact on the child

Feedback from carers about the changes they had seen in their child(ren) that they attributed to LTFI-LD was very mixed, and not all carers felt that the intervention had been ‘successful’. Carers were unanimously supportive of the intervention and were pleased that it had been available to their child(ren), but some felt that it had not been sufficiently tailored to address their child’s needs.

In some cases (but not all), carers were confident that the intervention had helped the child understand more about healthy relationships, appropriate (and inappropriate) sexual behaviour, and be better able to identify potentially harmful situations in the future. For some carers, this was described as the child being better able to protect herself; others felt that the child was still vulnerable to abuse (in all forms) but would be more likely to disclose immediately. This was seen as an important development. Where it had been identified, inappropriate sexualised behaviour and potentially harmful sexual behaviour had been addressed:

I think they are both just so much more rounded. They understand the world a bit better, and they certainly understand what’s right and what’s wrong regarding sexual abuse.
Other positive impacts attributed to the intervention included children’s mood improving, cessation of self-harming behaviour, reduced anger and defiance, and presenting more confidently. Some carers noted that their child was more communicative, which they attributed to the NSPCC intervention (with both the child and the carer).

The one young person who participated explained that although she was shy and nervous at the start of the intervention, it had helped “get my anger out, and talk to my mum more”.

Not all carers were satisfied that the intervention had adequately addressed healthy sexual relationships, and for some, there was a real concern that the child remained vulnerable to forming inappropriate relationships and/or experiencing further sexual abuse. Some carers considered that the child may either need to be re-referred to the NSPCC for further intervention when they were older, or that a different service may be required. Other concerns mentioned included continued enuresis, and the child’s conflicted feelings about the alleged perpetrator, which the carers considered had not been fully addressed. Carers in the main attributed these continuing concerns to the child’s learning disability rather than the sexual abuse they had experienced. Like CSPs, carers in many cases felt that the work was unfinished. In spite of these reservations, they were unwilling to be critical of the intervention; rather, in all cases they reported that the NSPCC practitioners had worked well with the child. Carers recognised that the intervention was a pilot and wanted the NSPCC to continue offering the work to children with learning disabilities, and to develop both the intervention and the practitioners’ skills.

We wouldn’t have been without it. I’m very impressed that they could even try. Yes, nobody else wanted to step up. There is nothing out there. If they don’t try, make loud mistakes, get it right next time. It’s absolutely fine, we don’t mind. We’d rather that they made these mistakes than that they just said, “There isn’t a service available.”.

Perceptions of the safe carer intervention

All carers interviewed for the study had attended safe carer sessions as part of LTFL-LD, although the number of sessions varied enormously, from three to 30. Like the child’s intervention, views on carer sessions were mixed, although all carers were appreciative. Again, flexibility about the practical arrangements for safe carer sessions was important. Some carers chose to arrange these sessions simultaneously with their child’s sessions to minimise travel and avoid the need to arrange alternative child care. Others preferred the sessions to be on a different day. In two families, carer sessions took place in the carer’s home.
(While these carers preferred this, CSPs noted that the work was more difficult to deliver and boundaries more difficult to maintain when outside a defined ‘therapeutic space’).

Most carers were appreciative of the support and advice the CSP had given them in dealing with aspects of the child’s difficult behaviour. These included tools to help calm and relax the child; better sleep routines; strategies to deal with perceived defiance; and coping with and understanding hyper-arousal. Some carers were encouraged to spend more one-to-one time with their child and while for busy carers this was challenging, those carers appreciated taking this time and noted an improved relationship with the child as a result.

Carers also valued the sessions as a chance to talk about the challenges of caring for a child with learning disabilities, and the impact of discovering the sexual abuse, openly and honestly. Carers frequently described the sessions as a chance to ‘rant’ or ‘whinge’ without fear of upsetting friends or family members:

> My sessions with [CSP], the first half an hour I would go in and whinge about whatever had happened with social work in the last week. Do you know what? That’s vital. There’s nowhere else I can whinge, because we can’t discuss what happens in this house. We don’t have friends, we can’t burden family. …Being able to go to [CSP] to dump, even if that wasn’t the purpose of the programme, is vital. Having somebody that you don’t have to avoid the words ‘sexual abuse’ when you’re talking about the crap that’s landed on you is vital.

Some respondents would have preferred the carer sessions to focus more on their own difficulties, including their mental health needs and trauma resulting from their own experience of abuse. While they recalled being signposted by the NSPCC to other services for this type of support, not all carers were happy to approach these services and would have preferred more intensive, ongoing support from the NSPCC practitioner.

### 3.4 Summary

The evidence from this evaluation of the LTFI-ID pilot is that the model can be successfully employed by NSPCC practitioners with previous experience of Letting the Future In. Supervision from team managers is a necessary requirement and support in the form of expert consultation from a specialist sexual abuse service (Respond) was also highly valued for more complex cases. Practitioners would value greater opportunity for joint supervision of CSPs working with children and carers from the same family.
The adapted version of LTFI allows more time for both therapeutic assessment and intervention than the original guide. This is because engaging a child, understanding their needs, building a therapeutic relationship and implementing an intervention plan that suits the child all tend to take longer with these children. These factors increased the complexity of the initial therapeutic assessment and required practitioners to be flexible in their approach and take the time to persist.

The practitioners were unanimous in their belief that the therapeutic relationship between the CSP and child was the core means through which recovery is generated. Interviews with family carers supported this view: most carers valued the relationship that their child built with their CSP, and for some respondents the strength of this relationship exceeded their expectations.

All of this is consistent with Allington-Smith and colleagues’ (2002) observation that psychoanalytical treatment approaches have the advantage of allowing children with learning disabilities to proceed at their own pace, and if the practitioner is sensitive, to enable these children to experience “being truly attended to by an adult that they are unlikely to have experienced before”.

Carers reported a range of positive impacts of the intervention on their children, including improvements in their children’s mood, increased confidence and greater ability to manage their feelings of anger and defiance, and the cessation of self-harming behaviour. However, carers felt the intervention had not sufficiently addressed the question of how to have healthy sexual relationships and in this sense that the work was ‘unfinished’. The NSPCC recognises that additional therapeutic help may be required as a child or young person grows older and moves through adolescence, and service centres encourage families to get back in touch for advice or further sessions in these circumstances.

Carers also reported that their children’s challenging behaviours could worsen immediately after starting the intervention, although they did improve after several months. This has also been reported in other studies (e.g. Peckham et al, 2007).

The coordination of the LTFI-LD intervention with advice, support and intervention from other agencies working with the family requires careful management. This is especially true where families are in conflict with other agencies and/or in receipt of support from multiple sources.
Carers valued their own intervention sessions with NSPCC practitioners and reported benefits included increased knowledge and understanding about sexual abuse and its impact; better coping strategies to manage their child’s challenging behaviours; improved relationship with the child; and increased confidence about protecting their child from further sexual abuse. Further, carers also valued the sessions as a chance to talk about the challenges of caring for a child with learning disabilities, as well as the impact of discovering the sexual abuse. Carers were particularly appreciative of the commitment of CSPs and their flexibility, contrasting this with the service they received from other agencies.

Safe carer work is often challenging, and both CSPs and carers reported difficulties in adhering to the primary purpose of safe carer sessions: to help the carer meet the needs of the child. Consequently, carer work has frequently gone on for longer, and for more sessions, than the guide suggests. While all staff perceive that safe carer work is a key strength of the LTFI-LD guide, they considered that its purpose is not always understood by the carers.
4. Evaluation tools

A set of evaluation tools was developed by the research team for use with all cases referred and accepted onto LTFI for the duration of the study. Two key outcomes for the formative evaluation included that children and young people experience the intervention as helpful, and that carers reported improved understanding and ability to respond to their sexually abused child. To help inform whether these outcomes were met, short feedback questionnaires were developed for use with all children, their carers and other professionals closely involved in the child’s life. These were developed after a rapid literature review found no standardised tools suitable for gathering feedback from this population (the review did identify potential measures for use in any future impact evaluation; see Chapter 5). Carers and children were asked to complete the measures towards the end of the intervention to minimise the impact of the evaluation on them.

In addition to the feedback questionnaires, tools were developed to capture: the range and nature of learning disabilities experienced by children referred and accepted for intervention; who in the child’s life is/should be involved in supporting the intervention; and children’s living and educational arrangements.

All cases referred and accepted onto the adapted version of LTFI between March 2015 and November 2017 were asked to participate in this aspect of the evaluation. An information sheet was developed for both carers and children, providing details of the study. Participation required consent for practitioners to share anonymised information about the child with the research team (using the referral mapping tool described below) and, towards the end of the intervention, completion of feedback questionnaires by carers and children.

CSP practitioners were trained by the evaluation team to manage the consent process and administer the evaluation tools. The research team did not have contact with families for this aspect of the evaluation, in order to retain their anonymity and to minimise disruption to the therapeutic process.

4.1 Number of cases consenting to the study

Data received from the NSPCC reveals that, between March 2014 and November 2017, there were 29 children referred, accepted and who had consented to the intervention. Of these, 13 also consented to the evaluation, including that CSPs, carers and children would complete data collection tools to be shared with the evaluation team.
Of the 16 cases for whom consent to participate in the evaluation was not given, four were referred before the data collection for the evaluation began (March 2015). Six cases were open for less than three months and were closed before the therapeutic work had begun. The remaining six cases were ongoing, and the child was engaged in therapeutic work, but the child and carer had not consented to take part in the evaluation. We did not ask CSPs to record reasons for non-consent.

For all evaluation tools, therefore, the total number of cases for whom data could have been completed is 13. This is very low, and caution needs to be exercised in interpreting the findings.

4.2 Description of tools

Intervention Feedback Questionnaires

Carers
A ‘Carer Feedback Questionnaire’ (CFQ) focused on the following five areas: impact of the intervention on themselves; factors influencing this impact; relationship with the NSPCC practitioner; impact on the child; and an open question about any further information they would like to feed back to the evaluation team. These forms were based on carer feedback forms developed for the evaluation of LTFI. They were given to carers at the end of the intervention and returned to the service centre in a sealed envelope to be sent directly to the evaluation team; they were not seen by CSPs or any other NSPCC staff. In total, 10 out of 13 carer feedback forms were returned.

Children and young people
We also aimed to include similar feedback from children and young people themselves. We developed three versions of a questionnaire asking for feedback on the intervention, their relationship with the CSP, and any impacts they may have experienced. Versions 1 and 2 asked the same questions, but one also had pictorial representations on all questions and scales. Version 3 was a very simple, open-ended question. Practitioners chose which version they felt was most suited to the child. Like the CFQ, children and young people were encouraged to complete the questionnaire away from the service centre, so it would not be seen by their practitioner; however, in some cases children preferred to complete the form with their practitioner present and, while acknowledging the potential bias, the evaluation team were clear that any method of allowing children’s voices to be heard throughout the study was better than none. In total, nine were returned.
The professional team around the child
A third feedback questionnaire was developed for use by the professionals closely involved in the child’s life. These were identified by the CSP as professionals who may be best placed to observe potential outcomes for the child, and/or who may have been affected themselves by the intervention (changes in care responsibilities and tasks; impact of the child’s behaviour on them etc.). The topics included questions on: impact of the intervention on them; contact with the NSPCC practitioner; impact on the child; and an open question about any further information they would like to feed back to the evaluation team. In total, four were returned.

Referral and case closure forms
Two questionnaires were developed for CSPs to complete for all cases accepted onto LTFI-LD where the family consented to inclusion in the evaluation. The referral mapping form was intended for completion during the therapeutic assessment phases, and the case closure form at the end of the evaluation (this would allow any changes during the course of the intervention to be reported). The purpose of these forms was to capture, for as many cases referred to LTFI-LD as possible, the following information:

- the nature of learning disabilities experienced by children referred to LTFI-LD, including communication skills and behaviours that challenge
- the nature of the sexual abuse experienced by the child
- the child’s living arrangements
- the child’s educational arrangements

In total, 13 referral mapping forms were returned and eight case closure forms (the remaining five cases had closed but the CSP did not return forms to the evaluation team). The number returned was very low, and caution needs to be exercised in interpreting the findings. We report here only a descriptive account of the data; any further statistical analysis would be inappropriate. In all cases where forms were returned – both those completed by NSPCC staff and service users – almost all questions were completed, indicating that should the NSPCC continue to use them, the data collected would likely be useful for statistical analysis should they be collected in significant number.
Nature of disability experienced by children referred to LTFI-LD

Of the 13 referral mapping forms received, six children were described as having a mild learning disability, six moderate, and one with a severe learning disability. Three also had a physical impairment, four had sensory impairment, and four autistic spectrum disorder. Two were reported to be experiencing mental illness and four were in receipt of support from child and adolescent mental health services.

All children used speech as their main form of communication, with one child also using sign language on occasion.

CSPs were also asked what was known about the presence of behaviours that challenge. The most frequently reported known behaviours were difficulties forming or maintaining relationships (11), depression/low mood (11) and anxiety (10). Some children were known to present aggressive behaviours including verbal aggression (8), defiance and flouting boundaries (7), physical aggression (6) and destroying things (5). Seven children were known to have self-harmed or to have threatened to. Five were presenting with age-inappropriate sexualised behaviour. No child was reported to be known on referral as misusing drugs or alcohol or engaging in criminal behaviour.

The child’s living and educational arrangements

On referral, three children were living with foster carers; the remainder (10) were at home with their birth parent. Six children were in mainstream school or FE college; four in a special school, and three were home educated.

Other professionals involved with the child

Ten of the 13 children had at least one other professional involved at the time of their referral, and there were often multiple professionals involved (one child had seven at the time of referral).

Common professions involved included social workers (8), speech therapists (5), psychologists (3) and community paediatricians (4). Education professionals also featured in seven children’s lives, including educational psychologists, teachers, SENCOs and education welfare officers.

Nature of the sexual abuse experienced by the child

Only eight case closure forms were returned to the team, so data collected on the nature of sexual abuse experienced by children on LTFI-LD is not reported here; however, those forms that were returned were completed in full.
4.3 Feedback from service users

Carers’ views on carer sessions

Carers were asked 10 questions about how the safe carers sessions had helped them. Of the 10 responses received, all “agreed” or “strongly agreed” that the sessions had increased their knowledge and understanding about sexual abuse and how to protect the child from further abuse, and had helped the carer support the child’s use of LTFI-LD sessions.

There was slightly less, though still high, agreement with the following statements: helped to re-establish a good relationship with the child (9 carers agreed); helped understand the child’s needs better (9); helped deal with negative feelings about the child's abuse (7); helped cope with feelings of isolation following the child’s abuse (6); helped cope with feelings of stress/anxiety following the child’s abuse (7); helped with feelings of sadness/depression (7); helped deal with feelings about the perpetrator of the abuse (6).

When asked what aspects of LTFI-LD were most helpful, all 10 carers “strongly agreed” that seeing their child make progress, and their own relationship with the child’s CSP, was helpful to them. All agreed that information given by the NSPCC service centre was helpful. Nine agreed that their individual carer sessions were helpful (one respondent did not attend any of these), and eight found the joint sessions with the child helpful (again, the remaining two did not attend these).

Eight carers reported finding the NSPCC’s contact with other professionals in the child’s life helpful. Three carers said that support from other professionals had been unhelpful.

Most respondents used the additional free text space to comment further and in all cases the comments were positive about LTFI-LD. A sample is provided below:

NSPCC pushing to get all the other professionals in our family life to work together to bring hope of resolution to long-term problems.

The NSPCC felt like they were on our side as a family – rather than try and put us back onto some sort of correct path they just supported us to get there on our own, which was helpful and affirming.

It wasn’t just about [child’s] abuse, it helped with other things, e.g. my child’s learning needs, team around the child meetings, housing, my child’s mental health.
Children’s views on their children’s services practitioner

Six children completed versions 1 and 2 of the child feedback questionnaire. In it they were asked to indicate how much they agreed with three statements about their CSP. In response to the statement ‘I liked spending time with my worker’, five children said “yes” and one “mostly”. In response to the statement ‘My worker helped me make changes in my life’, five children said “yes” and one “a little”. In response to the statement ‘My worker helped me to feel better’, four children said “yes”, one “mostly” and one “a little”.

Impact on the child

Carers were asked to indicate whether they had perceived any changes in the child’s mood or behaviour since referral to LTFI-LD. After the review of the literature concerning trauma symptoms in children with learning disabilities reported above, a list of 32 potential moods/behaviours was developed, and carers indicated whether they had seen improvement, no change, or a deterioration in each one. Carers could also indicate that the behaviour/mood had never been a problem for their child.

Table 2 summarises the 10 carers’ responses to each of the 32 moods and behaviours.

Carers were most likely to report seeing improvement in children’s moods or behaviours in the following areas: knowledge and understanding about appropriate sexual behaviour (8); capacity to protect self from further abuse (8); child’s relationship with the carer (7); and communication skills (7). Some carers also reported that some issues had worsened for their child, including defiance and flouting boundaries (2) and destroying things (2).

Six respondents also made use of the free text space to add comments about the impact of the service on their child, and all but one of these was unequivocally positive. For example, one carer wrote:

[Child] has generally improved all round. She is much calmer, more compliant and tends to think things through. She is making more and more good choices and is finally understanding that her history [of abuse] was not her fault, should never have happened and recognises those who failed to protect.
Table 2. Carer feedback form responses for changes in the child’s mood and behaviours (n=10)

<table>
<thead>
<tr>
<th>The child’s...</th>
<th>This has improved</th>
<th>This has no change</th>
<th>This has got worse</th>
<th>This has never been a problem</th>
<th>No response</th>
</tr>
</thead>
<tbody>
<tr>
<td>general mood</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>sleep patterns</td>
<td>3</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>confidence</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>eating patterns</td>
<td>2</td>
<td>6</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>avoidance of people or places</td>
<td>3</td>
<td>6</td>
<td>0</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>communication skills</td>
<td>7</td>
<td>3</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>physical health</td>
<td>2</td>
<td>5</td>
<td>0</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>feelings of shame or guilt</td>
<td>4</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>personal hygiene</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>capacity to protect him/herself from sexual abuse</td>
<td>8</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>anxiety and stress level</td>
<td>6</td>
<td>3</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>knowledge and understanding about appropriate sexual behaviour</td>
<td>8</td>
<td>1</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>self-esteem</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>capacity to make friends</td>
<td>3</td>
<td>3</td>
<td>1</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>nightmares/disturbed sleep</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>relationship with me</td>
<td>7</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>0</td>
</tr>
<tr>
<td>relationship with siblings</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>relationship with other carers/professionals</td>
<td>5</td>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>bed wetting/soiling (or in daytime)</td>
<td>2</td>
<td>0</td>
<td>0</td>
<td>8</td>
<td>2</td>
</tr>
<tr>
<td>defiance and flouting boundaries</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>verbal aggression</td>
<td>1</td>
<td>2</td>
<td>1</td>
<td>6</td>
<td>0</td>
</tr>
<tr>
<td>physical aggression</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>5</td>
<td>0</td>
</tr>
<tr>
<td>destroying things</td>
<td>2</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>difficult behaviour in school</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>difficulties forming or maintaining relationships</td>
<td>3</td>
<td>6</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>sabotaging intended positive experiences</td>
<td>1</td>
<td>3</td>
<td>0</td>
<td>5</td>
<td>1</td>
</tr>
<tr>
<td>running away/absconding</td>
<td>2</td>
<td>3</td>
<td>1</td>
<td>3</td>
<td>1</td>
</tr>
<tr>
<td>actual or threatened self-harm</td>
<td>3</td>
<td>4</td>
<td>1</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>sexualised behaviour (age-inappropriate)</td>
<td>2</td>
<td>3</td>
<td>0</td>
<td>4</td>
<td>1</td>
</tr>
<tr>
<td>criminal behaviour</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>alcohol misuse</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>0</td>
</tr>
<tr>
<td>drug misuse</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>9</td>
<td>0</td>
</tr>
</tbody>
</table>
The one equivocal carer had regrets about changes to the spontaneity and openness of the child’s behaviour as a result of LTFTI, which the carer nevertheless felt were necessary to protect them from further abuse. Unfortunately, these changes had constricted the child’s relationship with family members.

He is less open with his body language, which is a major positive for keeping himself safe. But [this] has damaged some of the non-verbal support he needed from me because of his ASC [Autism Spectrum Condition] – [it was] probably necessary but painful as a family for him to have to change because people abuse others, not because what he was doing was wrong intrinsically.

An important theme was that carers felt that the whole family was supported from the start:

Our case is complex and has involved 5 team members working for the support of our family including the CSP. The CSP set the tone, was our first contact, and created a feeling that the NSPCC understood our needs and were responsive to our particular circumstances – something we had not met in other professionals. She has fought our corner for the whole child, not just the things he needed to recover from abuse. The impact on our whole family has been to make us feel listened to and supported as individuals with needs but also as a family unit, again rare in our work with other professionals.

And another carer was only disappointed that this support was having to come to an end:

The LTFTI course [sic] seems well structured. For a pilot, I guess [child] was a bit of a challenge! It is a pity, but completely understandable within the goals of the programme and funding that we should be finishing [LTFTI]. But since we are still completely embroiled in the aftermath [of the abuse] as a family – child protection plan, social work, legal bits etc, I wish that we could have stayed here [with NSPCC] where we felt supported and understood. None of the other professionals have spent a fragment of time with either the children or us that the NSPCC have, and we really appreciated having you in our corner.
Views of professionals

Four professionals, two social workers and two school staff completed the professional feedback form about four separate children in the study. They were asked to comment on any changes in mood or behaviour they had observed in the child, using the same 32 items as carers seen in Table 2 above. Unlike carers, professionals were able to respond “don’t know” to each item and this response was used on several occasions, indicating professionals’ lack of knowledge. No professional reported that any mood or behaviour had worsened during the child’s time on LTFI-LD. Improvements were most likely to be reported in reduced anxiety and stress (all 4 children); general mood (3); confidence (3); avoidance of people or places (3); communication skills (3); shame or guilt (3); capacity to protect self from further abuse (3); self-esteem (3); capacity to make friends (3); difficulties forming or maintaining relationships (3); and age-inappropriate sexualised behaviour (3).

All four professionals made use of the free text space to comment further – these included the following:

This child has a diagnosis of ADHD so differences in behaviour are difficult to measure. However, we feel that this child has benefitted immensely from the support he has received.

LTFI was the best programme this child could have ever been involved with. I would recommend it to any child with similar needs.

This programme was very positive for this young person.

The child had already started work with the NSPCC when we first met. I knew she loved her sessions at the NSPCC and they have really helped support her. She speaks very fondly of her NSPCC practitioner.

Children’s feedback

Six children completed the feedback form in which they were asked to indicate changes they had experienced during their time on LTFI-LD. Their responses to each of the nine statements are shown in Table 3. It is noticeable that all children thought that they were better able to keep themselves safe, and that the five children who had previously lacked confidence felt better about themselves.
Table 3. Child feedback responses (n=6)

<table>
<thead>
<tr>
<th></th>
<th>This has got better</th>
<th>There has been no change</th>
<th>This has got worse</th>
<th>This has never been a problem for me</th>
</tr>
</thead>
<tbody>
<tr>
<td>My general mood (how happy or sad I feel lots of the time)</td>
<td>5</td>
<td>1</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Problems with nightmares or sleeping badly</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td>My self-confidence (how I feel about myself)</td>
<td>5</td>
<td>0</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>How I get on with my family</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>How I communicate with other people</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Feeling ashamed or guilty (thinking I did something wrong)</td>
<td>4</td>
<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Feeling angry</td>
<td>3</td>
<td>2</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>Being able to keep myself safe</td>
<td>6</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>Feeling worried or stressed</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>0</td>
</tr>
</tbody>
</table>

Five of the six respondents also used the free text space to say more about their thoughts on the service. These were all positive and included the following:

Learned about laws. Let my point of view been shared with mum. Grew trust between mum and I.

I was petrified about boys but now I have a boyfriend and I am a lot better.

More confidence. Talking more. Worked hard. I have enjoyed the sessions.

4.4 Summary

The number of cases for which evaluation tools have been completed was very low (n=13) and caution is necessary in any interpretation of the findings. This is due to a combination of a low number of referrals to the service (29) and then not all of these cases completing the programme, completing in time to take part in the evaluation or consenting to take part in the evaluation. Further research would be needed to explore the reason for the low referral numbers to the programme, but this may be partly explained by the issues identified from the literature review about the low numbers of children with mild to moderate learning disabilities in the population and then the number of those who have been sexually abused.
The majority of children referred to LTFI-LD had mild or moderate learning disabilities (not severe). They often experienced additional challenges including physical or sensory disability, and present with challenging behaviours that commonly included difficulties forming and maintaining relationships, depression, and anxiety. Over half of this small sample were educated outside mainstream provision. Most children also had at least one other professional from health or social care involved in their lives at the time of their referral to LTFI-LD. In short, these children had complex and challenging lives.

The carers felt that they benefited from sessions with NSPCC practitioners, in particular through increased understanding about child sexual abuse. They also reported seeing positive impacts on their child, which they attributed to the intervention. Most reported seeing improvements in the child’s understanding about appropriate sexual behaviour and increased capacity to protect themselves from further abuse. Further benefits were also reported by most carers.

The six children and young people who provided feedback also clearly found the intervention helpful. They liked spending time with their NSPCC children’s services practitioner (CSP) who, they felt, helped them make changes in their lives. Most of these children reported improved mood, self-confidence and, very importantly, the capacity to keep themselves safe.

Although the quantity of data available is low, it is very encouraging that these findings are strongly aligned with those of the qualitative case studies with families.
5. Further evaluation of LTFl-LD

5.1 Limitations of the current formative evaluation

This formative process evaluation has been hampered by a low level of recruitment to the intervention and consequently to the evaluation, and by the small number of teams who have been delivering LTFl-LD for long enough to comment on its implementation and perceived effectiveness.

Take up of the service by parents/carers and children was much slower than the NSPCC had expected and even though the evaluation was suspended to allow more time for recruitment, the numbers of children receiving the service remained low, totalling 29 over three and a half years. This was much lower than the NSPCC had anticipated and might be expected from the epidemiological evidence reviewed in Chapter 1. LTFl itself received plenty of referrals to most of its service centres and in many areas its provision was well known, with a high reputation. This evaluation did not focus on the pathways to the service and we do not have the perspective of referrers. There may still be a general assumption that children with learning disabilities are unlikely or unable to benefit from psychological interventions (Sinason, 2002; Cooke & Standen, 2002; Hollins & Sinason, 2000). Nationally, psychological services for these children are underdeveloped; a recent review described services as “woefully inadequate” (Rossiter et al, 2015). Some services are notionally provided by CAMHS, but Rossiter and colleagues questioned whether these services had sufficient skills and experience in working with intellectual disability.

Some of the 29 cases had started before the evaluation commenced and others declined to participate in the evaluation; consequently the number of cases with consent for the evaluation and completion of the evaluation tools was only 13. This low number of respondents also introduces a potential for bias (it is possible that carers and children who did not feel positively about the intervention were less likely to complete a feedback form) and means that we cannot draw definitive conclusions from the evaluation tools.

This also resulted in having a limited population from which to draw the sample of families involved in qualitative case studies, and all four families were drawn from the same NSPCC team. Consent was given to speak to only one child from these four families. Similarly, it was possible to carry out case studies with only two NSPCC teams because the others were not sufficiently experienced in using LTFl-LD. This means that we can draw only tentative lessons for the continued development of the intervention.
5.2 Recommendations for further evaluation

The NSPCC are currently rolling out the delivery of LTFI-LD to 10 teams, which will likely facilitate greater numbers of children and carers using the service. The NSPCC have agreed to continue using the data collection tools developed for the current study with all teams (and all teams have been trained in their use by the University of Bristol). This should facilitate mapping the range and nature of learning disabilities experienced by children accepted for the intervention, and the outcomes that children, their families and professionals attribute to the intervention.

We would recommend allowing teams to gain experience of the delivery of the intervention over time, and with a greater number of children and carers, before further qualitative work is undertaken. Despite the limitations of the current study, we believe that both the team and family case studies have revealed some useful early findings. Further qualitative work with a greater range of both teams and children will likely prove valuable.

In addition, given the paucity of existing summative evaluations of the outcomes of therapeutic interventions, further study would be very appropriate. These early findings suggest children with learning disabilities and their carers can and do benefit from therapeutic intervention after sexual abuse and, should the service continue to grow in number, it may be possible to undertake the first proper impact evaluation of such a service for this population.

In the first instance, a straightforward ‘before’ and ‘after’ evaluation would be advisable, with the added benefit that the research assessments would be able to inform the practitioners’ therapeutic assessments for LTFI-LD. In the likelihood that the intervention would last a year or more in many cases, reassessment at six-month intervals would be very worthwhile, together with follow-up at a further six months and 12 months after the end of the intervention.

Assuming sufficient numbers of children engaged in the service with consent for participation in the research, the results would provide valuable information on whether or not the intervention was effective and for which children. This would be the basis for defining the parameters of a randomised trial. The challenge remains to identify suitable outcome measures for such an evaluation.
5.3 Consideration of measures for a summative evaluation

The scoping review sought to identify treatment outcome measures suitable for use for children and young people with learning disabilities who had been affected by sexual abuse.

The Guide to using outcomes and feedback tools for children, young people and families, published by the Child Outcomes Research Consortium (CORC), aimed at clinical practitioners, neatly summarises the difficulties in using standardised measures with children with learning disabilities (Rossiter, 2014). First, there will be concerns about the psychometric properties (reliability and validity) of scales and measures that have been developed with ‘typically-developing’ children. Second, children with learning disabilities may have difficulties understanding questions, be less able to self-report, and/or items and questions may be inappropriate for them. Finally, standardised measures may not be sensitive enough to detect changes that may occur in children with learning disabilities as a result of intervention, as these changes in adaptive behaviours or development can often be very small in this population, particularly for those with severe learning disabilities or profound and multiple disabilities (Rossiter, 2014, p.109).

Ideally, outcome measures should be developed specifically for this population. However, a systematic review focused on the clinical effects of sexual abuse in people with learning disabilities found that there was no standardised diagnostic instrument specifically designed to assess the impact of trauma in people with learning disabilities (Sequeira & Hollins, 2003). Wigham et al (2011), in their review of the effects of traumatising life events on people with learning disabilities, echo this point: “The review also suggests the lack of psychometrically sound measures of life events and trauma for people with intellectual disabilities”. While both studies focused predominantly on adults, neither found a measure suitable for children with learning disabilities.

Mevissen and colleagues (2016) have been addressing the lack of measures by developing an adapted version of the PTSD clinical interview (Anxiety Disorders Interview Schedule for Children [ADIS-C] PTSD section) for children with mild to borderline learning disabilities. The adapted measure was used with 80 children with mild learning disabilities and their caregivers and was found to have excellent inter-rater validity and good convergent validity with other measures of PTSD. The authors noted that this is the first study to validate a PTSD clinical interview for such children and claimed that research on the outcomes of interventions for PTSD in this population could develop because symptoms can now be measured in a standardised and reliable way. This is the only measure...
of PTSD for children with learning disabilities that we have been able to find, and it needs to be tested in other centres and services. The drawback is that the clinical interview has to be undertaken by trained psychologists – it comprises 26 ‘event’ questions and 37 ‘symptom’ questions, and as such, is time consuming and expensive.

As noted above, the effects of sexual abuse on children with learning disabilities are likely to be wide ranging and not limited to PTSD; they may also include challenging behaviours, anxiety, depression and/or changes to adaptive behaviours. The CORC review of tools for use with children with intellectual disabilities provides useful information on the efficacy and appropriateness of specific tools (Rossiter, 2014). A summary of this review is provided in Table 4.

Mulligan and colleagues (2014) have described the use of two outcome measures recommended by CORC – the Strengths and Difficulties Questionnaire (SDQ) and the parent version of the Development Behaviour Checklist (DBC-P). These were used in a family support service in Sussex for children and young people with learning disabilities. The service is designed for children presenting with challenging behaviours, which may have included children affected by sexual abuse, but this is not mentioned.

The SDQ is widely used in England; it is a general, standardised outcome measure for children and young people and its use is required for children looked after by social services and in CAMHS. There are age-related versions for use by the children themselves, their parents/carers and teachers. Its appropriateness for children with learning disabilities has been questioned; the norms are based on the general child population, so it is not sensible to ‘read across’ to learning disabilities. However, Mulligan and colleagues (2014) found that the parent report SDQ at baseline assessment and at follow-up one year later showed statistically significant changes on subscales measuring external expressions of distress. However, the subscale measuring (internal) emotional distress and therefore the overall score did not change; this may be because the parent report version is insensitive to change or because the service was ineffective in this area.

Unlike the SDQ, the DBC-P is a measure specifically designed for children with learning disabilities, and Mulligan and colleagues’ (2014) evaluation found that mean total scores were considerably over the clinical threshold at both baseline and follow-up. There was a statistically significant reduction in these total scores at follow-up but not in any of the individual subscales, although they were trending in that direction.
## Table 4. Child Outcomes Research Consortium (CORC) recommendations for outcome measures for use with children with learning disabilities

<table>
<thead>
<tr>
<th>Tool</th>
<th>Description</th>
<th>Use with children with learning disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997)</td>
<td>A behavioural screening questionnaire about 3–16-year-olds with five subscales: emotional symptoms; conduct problems; hyperactivity/ inattention; peer relationship problems; and prosocial behaviour</td>
<td>CORC recommend use with children and young people with mild learning disabilities, but not severe and profound. Emerson (2005) reports that the child, carer and parent forms appear to provide a robust measure for those with mild learning disabilities.</td>
</tr>
<tr>
<td>Revised Children’s Anxiety and Depression Scale (RCADS) (Chorpita, 2000)</td>
<td>A 47-item questionnaire for children and parents measuring frequency of symptoms of anxiety and low mood. Includes subscales on separation anxiety, social phobia, generalised anxiety, panic, obsessive compulsive, and low mood.</td>
<td>Appropriateness of use for children with ID is largely untested, and feedback from families and clinicians is that items may lack relevance for children with learning disabilities.</td>
</tr>
<tr>
<td>Nisonger Child Behaviour Rating Form (Aman, 1996)</td>
<td>A standardised tool for assessing child and adolescent behaviour, developed for children with learning disabilities. Subscales include positive social behaviour, and problem behaviour including conduct, insecure/anxious, hyperactive, self-injury/stereotypic, self-isolated, and overly sensitive.</td>
<td>Recommended by CORC for use with children with more severe learning disabilities, but criticism includes inappropriateness of items, complicated scoring system and negative language.</td>
</tr>
<tr>
<td>Developmental Behaviour Checklist (DBC-P DBC-T) (Einfeld &amp; Tonge, 1992; 2002)</td>
<td>Completed by parents or other carers or teachers, reporting problems over a six-month period. 96 items for the assessment of behavioural and emotional problems of young people aged 4–18 years with developmental and learning disabilities.</td>
<td>Has the advantage of being specifically developed for children with learning disabilities, and is comprehensive.</td>
</tr>
</tbody>
</table>

5.4 Summary

Evaluating the impact of the intervention will be challenging but is recommended. The roll-out of the intervention to 10 teams may offer an opportunity for further qualitative and quantitative work with a greater number of children and carers in receipt of LTFI-LD.

As the literature review identified, there is a paucity of evidence for the sequelae of sexual abuse for children with learning disabilities, as well as a lack of studies evaluating treatment options. The effects of sexual abuse on children with learning disabilities are wide ranging and not limited to trauma, and may include challenging behaviours, anxiety, depression and/or changes to adaptive behaviours.

We should not assume that all children referred to the service will have symptoms of PTSD; this was certainly not the case for children and young people included in the evaluation of LTFI (Carpenter et al, 2016). It is important to know whether children are traumatised in this way because this should be part of the therapeutic assessment (which is why LTFI employs standardised measures i.e. the Trauma Symptoms Checklist). Consequently, it would be advisable to assess trauma using the one validated measure we were able to find. This is Mevissen and colleagues’ development of an adapted version of the PTSD clinical interview (Anxiety Disorders Interview Schedule for Children [ADIS-C] PTSD section) for children with mild to borderline disabilities. This would require administration by a psychologist or an assistant psychologist with supervision.

Parent and teacher report measures may be used to assess behavioural and emotional problems, which may or may not be related to their experience of sexual abuse. CORC recommends the use of the Developmental Behaviour Checklist (DBC-P DBC-T) (Einfeld & Tonge, 1992; 2002), which has been specifically adapted for the assessment of behavioural and emotional problems for young people aged 4–18 years with developmental and learning disabilities. It is lengthy but was completed by parents and would certainly inform the therapeutic assessments.

The Strengths and Difficulties Questionnaire (SDQ) (Goodman, 1997) is also completed by parents/carers and there is another version for teachers. It measures emotional symptoms, conduct problems, hyperactivity/inattention, peer relationship problems and prosocial behaviour in children. It is very well recognised as an outcome measure and its use is required in CAMHS and looked after children’s services. Although its use with children with learning disabilities is not yet fully established, it provides the kinds of data that commissioners are looking for and it is recommended by CORC.
6. Summary and recommendations

Children and young people with learning disabilities are at greater risk of sexual abuse than their non-disabled peers. The effects of sexual abuse on this population is less well understood than for the general population of children. Furthermore, even less is known about the efficacy of interventions to support children with learning disabilities to recover from the effects of sexual abuse.

The small amount of literature available suggests that psychoanalytically-informed creative therapies may be useful, along with cognitive and behavioural approaches, all of which have informed the development of LTFI-LD.

The pilot of LTFI-LD involved fewer NSPCC teams than expected, and fewer children referred and accepted onto the intervention (and who consented to the research study). As a result, the number of cases that could be included in this formative process evaluation is very low and findings are tentative. Further research would be needed to fully understand the reasons for the low referral numbers to the service.

Nevertheless, it is encouraging that both the qualitative interviews with carers (and one child), NSPCC practitioners, and quantitative feedback received from 13 cases, indicated that all stakeholders perceive that LTFI-LD benefits both children with learning difficulties and their carers.

Positive impacts on children reported by carers, children, and practitioners include improved mood, increased confidence, and a reduction in the frequency and type of challenging behaviours. There was less agreement over whether the intervention had been successful in supporting children with learning difficulties to avoid further abuse, and recognition that as children grow and develop, further intervention may be necessary.

Carers can also benefit from intervention, including support to understand the effects of sexual abuse and to support their child’s recovery; and support with their own difficulties, including the daily challenges of caring for a child with learning disabilities and the interaction with other agencies.

The coordination of the LTFI-LD intervention with advice, support and intervention from other agencies working with the family requires careful management. This is especially true where families are in conflict with other agencies and/or in receipt of support from multiple sources.
The most important aspect of LTFI-LD (in comparison to the intervention for other children) is the greater time allowed for both assessment and intervention.

This is complex work, and the evidence from this formative evaluation is that LTFI-LD can be successfully employed by NSPCC practitioners with previous experience of therapeutic intervention with children affected by sexual abuse. Not all practitioners had previously worked with children with learning disabilities and supervision by team managers is a necessary requirement. Support in the form of expert consultation from a specialist sexual abuse service (Respond) was also valuable for complex cases.

Given the paucity of evidence for the effectiveness of interventions aimed at supporting children with learning difficulties to recover from sexual abuse, further evaluation of the service is recommended. The roll-out of LTFI-LD to a greater number of NSPCC teams will facilitate this.

Both the team and family case studies have revealed some useful early findings and further qualitative work, with a greater range of both teams and children, will likely prove valuable. We recommend allowing teams to gain experience of the delivery of the intervention over time, and with a greater number of children and carers, before further work is undertaken.

Greater numbers of cases may also make possible the first impact evaluation of an intervention for this population. Identifying appropriate outcome measures is challenging as the effects of sexual abuse on children with learning disabilities are likely wide-ranging and not limited to trauma. We have identified potential measures for trauma, behavioural and emotional problems, which may both assist in therapeutic assessment and impact evaluation of the service.

The evidence so far suggests that LTFI-LD is a promising intervention for children and young people whose experience of sexual abuse and opportunities of recovery have not received the attention they deserve.

The main LTFI service is now being scaled-up to other organisations to deliver so that more children and families can benefit from the service. Planning will now take place for the LTFI service for children with learning disabilities to move into scale-up too. The service will be offered to organisations who have already taken on LTFI, as they will have already had the basic training. The planning for scale-up will include consideration of the training and support needs of staff delivering this intervention.
We conclude with a quote from one of the carers cited above:

We wouldn’t have been without it. I’m very impressed that they could even try. Yes, nobody else wanted to step up. There is nothing out there. If they don’t try, make loud mistakes, get it right next time. It’s absolutely fine, we don’t mind. We’d rather that they made these mistakes than that they just said, “There isn’t a service available.”.
7. References


Letting the Future In for children with learning disabilities is based on an adapted version of the original Letting the Future In guide. An outline of the original guide is given below.

**Letting the Future In: A brief summary**

The Letting the Future In guide is broken down into five parts (see below) but must be seen as a whole. Therapeutic work with sexually abused children and young people is both complex and emotionally demanding, and the detail and length of the guide reflects this. It demands the application of professional judgement at various points. There is material on supervision in Module 1 (Section 4) and again in Module 5 (Section 2), outlining the support practitioners will need from supervision when undertaking this type of work.

The overall goal of Letting the Future In is to integrate evidence-informed approaches that will equip practitioners engaged in working therapeutically with sexually abused children and young people to deliver effective and appropriate interventions, and, consequently, improve outcomes for them.

**What is the Letting the Future In guide?**

It is modular in format. Modules 1 and 2 provide the basis for delivering, and Modules 3, 4 and 5 are the ‘doing’ part. Activities worksheets and case examples support Modules 3, 4 and 5 but they are a small part and not intended to replace the practitioner’s own resources and wealth of existing tools and literature available.

Delivery is time-limited, with up to 20–24 face-to-face sessions for the original LTFI service, though the exact length is dictated by the needs of the child. Timescales for the adapted version of LTFI are less restricted, reflecting the increased complexity of working with children and young people with learning disabilities and the slower pace of the work.

**Module 1: Overall purpose**

Module 1 provides an introduction to the overall purpose and goals of the guide, the definition and impact of sexual abuse, and the evidence base. It has information about whom the guide is for and who it is intended to help. It places the context to the work within national and local guidance and procedures for protecting children and emphasises the importance of supervision.
Module 2: Context for working with sexually abused children and young people

The goal of Module 2 is to ensure that practitioners are familiar with the theoretical models and skills that underpin the intervention approach of Letting the Future In. It describes the value base for using the guide when working with children and young people who have been sexually abused. It provides an overview of the key theoretical models and the knowledge base for using the guide, going on to consider skills-based modalities.

Module 3: Assessment

Assessment in the context of this guide is for the purpose of establishing the therapeutic needs in relation to the impact of sexual abuse, and to establish which of the guide interventions are relevant for this child or young person and their carer. The importance of the assessment phase in working with sexually abused children and young people is emphasised in the module, and the revised regenerative model is introduced.

Module 4: Action

Module 4 focuses on two evidence-informed key areas: the intervention plan (for the child or young person) and support for the non-abusing parent or safe carer. There are distinct interventions, with an introductory context, some guidance and suggested tools to use, and illustrative case studies, further sources and references. The guide’s approach is to provide the practitioner with an overall structure and model to build an intervention plan for the individual child, continuing the revised regenerative model.

Module 5: Resolution

Module 5 deals with judging the timing of endings, but ideally planning for the ending happens right at the outset from the beginning (Module 3). There may be signs from the young person themselves and some of the indicators that they are ready to move on with their life. This module considers this and the use of supervision in ending.