

**Professionals' perception of the process of change during an attachment
based parenting intervention (Video Interaction Guidance) with parents
with intellectual disabilities**

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Executive summary

People with intellectual disabilities (ID) have impairments in intellectual and adaptive functioning, with a developmental onset. Increasing numbers of people with ID are becoming parents, but they often face an assumption of parenting incompetence, and their children are at greater risk of being taken into care.

However, the relationship between parental intelligence quotient (IQ) and parenting ability is not causal, and parents with ID are often exposed to a myriad of contextual factors which impact upon their parenting. The evidence suggests that parents with ID often benefit from evidence-based training programmes and informal support. Therefore, it is suggested that with the right support, parents with ID are able to raise their children effectively.

Paper 1: A systematic review of parents with intellectual disabilities' experiences of formal and informal parenting support

Introduction.

Parents with ID benefit from parenting interventions which build on their strengths, use modelling and praise and increase social inclusion. Longer periods of support produce changes that are most likely to be maintained over time, and a combination of formal and informal support best predicts outcomes. Although there are some limitations in the evidence base, there is general empirical support for the benefit of parenting interventions for parents with ID.

A systematic review exploring parents with ID's experience of formal parenting support found that while there was some ambivalence around the usefulness of the support, parents valued professionals providing practical and emotional support. Support was experienced most positively when supporters were reliable, trustworthy and good at listening.

However, parents with ID receive the majority of their support from family and other informal supporters, rather than professionals. The experience of informal support is under-explored. Therefore, the current systematic review explored how parents with ID experience formal and informal support for their parenting, in order to enable supporters to tailor the provision of support to the needs of this client group.

Method.

Three electronic databases were systematically searched for articles published up until February 2019. Search terms were used to explore each concept in the research question. In addition, reference lists of included studies were hand searched, and the researcher's knowledge of the literature was utilised. Inclusion and exclusion criteria were applied to the search results, resulting in the inclusion of 13 studies in the review.

The quality of the included studies was assessed using the Critical Appraisal and Skills Programme (CASP; 2018) checklist for qualitative research. All included studies were of at least moderate quality, and as such no studies were excluded based on the assessment of their quality.

Thematic synthesis was used to integrate the findings of the studies. A sensitivity analysis was used to assess the contribution of lower quality papers to the overall synthesis, and as a result a descriptive theme was removed from the final analysis.

Findings.

Five of the studies were classified as having a low likelihood of methodological flaws and the remaining eight studies had a moderate chance of methodological flaws.

Across the 13 studies, interview data was collected from 157 parents with ID, 22 of which were specified as fathers and 99 as mothers. Parenting support included support from community ID teams, parenting groups, advocacy, social support and pre- and post-natal care. The majority included parents who had children living at home with them, or had been removed from their care. The majority of studies used proxy reports of ID, and took place in the UK. Two studies took place in Sweden and one in Canada.

Qualitative data was collected using interviews in all studies, and three studies supplemented this data with observational data and field notes. Analysis was conducted mainly using grounded theory, Interpretative Phenomenological Analysis and thematic analysis.

The synthesis of the data led to the development of two themes and five subthemes. Parents with ID at times had a negative experience of support. This was due to the preconceptions held by others, a negative experience of the helping relationship, and

elements of support being experienced as unhelpful. However, parents also reported a positive experience of support. A positive helping relationship and elements of support being perceived as helpful contributed to this positive experience.

Discussion.

The results are discussed in line with Tucker and Johnson's (1989) conceptualisation of parenting support for parents with ID as inhibiting or promoting their competence.

Parents experienced support as inhibiting their competence when supporters assumed they were incompetent and scrutinised their parenting. For some parents, this experience led them to disengage from support which reinforced the belief held by supporters that they were incompetent parents.

The relationship with supporters promoted parents' competence when supporters listened to, understood and respected parents. This type of relationship was experienced as collaborative. However, supporters who were intrusive and critical inhibited parents' competence.

The support itself was experienced positively when adaptations for learning needs were made, when modelling was used and when supporters used positive reinforcement. Parents also valued support which addressed their emotional needs and reduced social isolation. When support was not in line with parents' own identified support needs, it was

experienced as competence inhibiting, which highlights the need for a strengths based assessment.

The clinical implications of the review are that supporters should align themselves with a narrative focusing on the successes and capabilities of parents with ID, and should support parents in line with good practice guidelines. Providing competence promoting support is best executed when supporters are under low strain, and thus services should provide supervision and respite for supporters. Supporters should strive to meet parents' emotional needs and increase social inclusion.

There are strengths and limitations of the review. While the studies were all of at least moderate quality, they often failed to make it explicit if they had adhered to best practice guidelines for interviewing people with ID. The samples were also mainly mothers and took place in western contexts, limiting the generalisability of the findings. The use of the CASP (2018) checklist is arguably a reductionist method of assessing the quality of qualitative studies and the variety of the support provided to parents with ID impacted upon the coherence of the analysis. Future research could adhere to interview guidelines, include fathers and participants in non-western contexts and explore how the experience of parenting support has changed over time.

Paper 2: Professionals' perception of the process of change during an attachment based parenting intervention (Video Interaction Guidance) with parents with intellectual disabilities

Introduction.

The evidence base exploring parenting interventions with parents with ID tends to focus on teaching practical parenting skills, rather than supporting the attachment needs of parent and child. An attachment based intervention increasingly being offered to parents with ID is Video Interaction Guidance (VIG). During VIG, a practitioner, known as a 'VIG guider', reviews videoed parent-child interactions with the parent and highlights moments of attuned parenting. The guider also models sensitivity and attunement in the therapeutic relationship.

VIG is widely supported as a parenting intervention for parents without ID, and there is some evidence exploring the use of video-feedback interventions with parents with ID. While some research has explored the process by which VIG achieves change for parents without ID, this has not been explored in the context of parenting with ID.

In order to address gaps in the literature, the current study explored the perspective of VIG guiders regarding the impact of VIG when working with parents with ID, and the factors that they believed facilitated or hindered the intervention.

Method.

Semi-structured interviews were conducted with nine VIG guiders who had worked with parents with ID. The guiders were all female and had worked in a range of settings. The interviews were transcribed and analysed using a grounded theory methodology, including line-by-line, initial and focused coding of data.

Results.

The results of the analysis produced 12 theoretical codes and 37 focused codes. These codes were developed into a model highlighting factors which facilitated and hindered the process of change during VIG with parents with ID, from the perspective of VIG guiders.

Before VIG, parents with ID tended to have a broadly negative view of their parenting and their child, limited parenting skills and low confidence. Parents often had a negative expectation for the intervention and were sometimes difficult to engage. The process of change was facilitated by parents seeing themselves interacting successfully on video, overcoming some of the difficulties with language associated with ID. Parents often experienced both positive and negative emotions during VIG, contributing to behaviour change. This was further reinforced by sharing successes with others. Parents began to develop a new, strengths-based narrative of their parenting ability, in contrast to a problem saturated narrative often held about parents with ID, and viewed their child in a more positive light.

VIG was reported to contribute to improvement in child development, the parent-child relationship, parenting skills, and the parents' relationship with their wider systems. These

outcomes were hindered by intrapersonal, interpersonal and contextual factors. The outcomes were facilitated by adapting the VIG protocol for parents' learning needs and providing mental health support. Guiders' own supervision, a focus on engagement and the social care context can also facilitate the intervention.

Discussion.

Broadly, the results suggest VIG guiders believed that parents with ID benefit from VIG, and the outcomes are comparable to those reported in the literature when conducting VIG with parents without ID. VIG is able to meet the goals identified by and for parents with ID and promotes social inclusion, which has multiple benefits for parents with ID.

The process of change was also broadly similar to the evidence base with parents without ID. VIG's strengths based approach encouraged the development of a new narrative, in contrast to the disabling narratives often perpetuated in society. The results found the difficulties related to ID and parental mental health needs impacted on the intervention which required ID specific adaptations.

The clinical implications of the research are that guiders should aim to promote the facilitating factors and limit the hindering factors. For example, guiders should make individualised adaptations for learning needs, facilitate support for parental mental health needs, utilise supervision, reflect on the impact of social care context and social narrative around ID, and spend time focusing on engagement. The study also highlights the utility of incorporating attachment theory into clinical work with parents with ID.

A strength of the study was its originality and adherence to guidelines for high quality qualitative research. A limitation of the study was its relatively small sample size, and deviations from the grounded theory methodology. Finally, the use of proxy reports of ID makes inferences about how IQ relates to VIG difficult to draw.

Future research could compare a formally adapted version of VIG, based on the research findings, with treatment as usual. In addition, researchers could develop outcome measures which are better able to capture change when conducting VIG with parents with ID.

Paper 3: Integration, impact and dissemination

Integration.

The research topic combines clinical, theoretical and personal interests of the researcher, including parenting interventions and work with marginalised groups. A reflective journal, often focusing on understandings and narratives around disability and epistemological assumptions, was used throughout the research process. There are similarities in the findings of both studies, including the emotional experience of support and the potential benefit of offering support to parents with ID. A notable difference in the results is that VIG guiders assumed parents had limited parenting skills and were unconfident in their parenting, a view which was not shared by parents.

Impact.

The research highlights that clinical psychologists, and the research they produce, has the

potential to have an impact at all levels of the system (Bronfenbrenner, 1992). At the individual level, therapy should be strengths based and empowering, and standard guidelines for supporting parents with ID should be adhered to. Social inclusion should be increased, which has the potential to safeguard children. Systems change, including staff training, has the potential to reduce the economic and emotional costs of placing children in care, thus improve quality of life. At the macro-level, policy should highlight the importance of incorporating attachment theory into work with parents with ID, and psychologists should strive to influence cultural values and stigmatised beliefs about parents with ID.

Dissemination.

The research has been disseminated to trainee and qualified clinical psychologists, and a summary will be sent to participants. Academic journals relevant to the research will be approached for publication. A poster presentation of the empirical paper has been accepted at a relevant international conference and an accessible dissemination strategy will be produced. A presentation of the findings and clinical implications of the research will be presented to VIG guiders with an interest in using the approach with parents with ID.

Paper 1: A systematic review of parents with intellectual disabilities' experiences of formal and informal parenting support

Abstract

Parents with intellectual disabilities (ID) face challenges to their parenting, but with the right support are able to raise their children effectively. While there are some methodological limitations in the research, reviews have shown evidence that parents with ID can benefit from parenting interventions. A systematic review of parents with ID's experiences of formal support explored the types of support received, the attitude and approach of professionals and the outcomes of being formally supported. However, parents with ID receive the majority of their support from informal supporters, and a combination of formal and informal support has been reported to best predict parenting outcomes. In line with this, the current review explores how parents with ID experience both formal and informal support, in order to extend the literature and provide guidance on how to improve the experience of parenting support for parents with ID.

Relevant search terms were used to search three electronic databases. Thirteen studies, with a total of 157 participants, met inclusion criteria and were critically appraised using CASP (2018). All studies were of at least moderate quality. Thomas and Harden's (2008) thematic synthesis approach was used to synthesise the findings of the studies. This identified five key themes: (1) experiencing the preconceptions of others, (2) experiencing the helping relationship positively, (3) experiencing the helping relationship negatively, (4) experiencing elements of support as helpful, and (5) experiencing elements of support as unhelpful. These results were understood within the framework of competency inhibiting and competency promoting support. Strengths and limitations of the systematic review and included studies are discussed. Recommendations for clinical practice are outlined,

including adherence to standard guidelines for supporting parents with ID and working with narratives around disability.

Keywords: parenting, learning disabilities, intellectual disabilities, parenting support, systematic review

Introduction

People with intellectual disabilities (ID) have impairments in intellectual and adaptive functioning, with a developmental onset (American Psychiatric Association; APA, 2013). Increasing numbers of people with ID are becoming parents, but they are known to face multiple challenges to their parenting (Schuengel, Kef, Hodes, & Meppelder, 2017) and their children are at greater risk of being taken into care (Booth, Booth, & McConnell, 2004). Although parents with ID often face a presumption of parenting incompetence (Gould & Dodd, 2014), many parents benefit from evidence-based training programmes (McConnell, Feldman, & Aunos, 2017) and informal support (McGaw & Newman, 2005) and evidence suggests that with the right support, parents with ID are able to raise their children effectively (Tarleton, Ward, & Howarth, 2006).

Llewellyn, Mayes, and McConnell (2008) outline three distinct phases in the research on parents with ID. The first stage, beginning in the 1940s, focused on the vulnerabilities that children of parents with ID are exposed to, and questioned whether people with ID should parent at all. As it became accepted that people with ID have the right to a family life, and should be provided with parenting support to enable them to thrive as parents (Department of Health; DoH, 2009), the attention of research began to shift, with the second phase focusing on the effectiveness of interventions offered to parents with ID. Evidence from this phase demonstrates parents with ID can adequately care for their children given appropriate support, which includes interventions which build on their strengths, use modelling, offer praise and increase social inclusion. Longer and more intense support produces changes that are most likely to be maintained over time (McGaw & Newman,

2005). This support should be provided by both professionals and informal support networks including family members, as the main predictor of adequate parenting by parents with ID is a firm structure of both informal and formal support (McGaw & Newman, 2005).

Wade, Llewellyn and Matthews (2008), reviewing this second phase of research, identified seven studies of parenting interventions for parents with ID. The interventions included teaching parents to break tasks down into smaller steps, modelling parenting skills, using praise and reinforcement, and visual aids as prompts. The studies, using valid and reliable outcome measures, supported the use of home-based behavioural training programmes to facilitate parenting skills. There were significant post-intervention differences between the intervention and control groups in parenting knowledge and behaviour in the two studies which employed experimental methods. The remaining five studies, which used quasi-experimental designs, suggested parents could be taught parenting skills. However, unstable baselines and missing data made conclusions on the effect of the interventions difficult to draw. The majority of studies included a follow up period, and found parenting skills were maintained over time. However, the generalisation of parenting skills was rarely evaluated, which questions the ecological validity of the evidence base. Further, Wade et al. (2008) highlighted that the majority of studies reviewed failed to empirically evaluate the impact of context on the outcome of interventions, which is known to impact parenting ability (Schuengel et al., 2017).

In an attempt to draw conclusions from higher quality research, a Cochrane review (Coren, Thomae, & Hutchfield, 2011), identified three randomised control trials (RCTs) of support

for parents with ID. These interventions reported significant post-intervention improvements in the mother-child interaction, child health outcomes and home safety skills. Although the studies reviewed used control groups, they had small sample sizes and limited use of blinding, questioning their validity. Additionally, as the reviewers did not identify studies reporting unsuccessful interventions, there may be a publication bias. Coren et al. (2011) concluded larger RCTs are needed before firm conclusions can be drawn about the effectiveness of parent training for this client group. Despite the limitations of the evidence base, it is generally accepted parents with ID can parent effectively, when adequately supported (Heinz & Grant, 2003; Murphy & Feldman, 2002).

In order to be effective, the support parents with ID receive needs to be acceptable to them (James, 2004), and Tucker and Johnson (1989) acknowledge that the provision of support alone is not sufficient to promote parenting competence in this client group. Parenting competence is promoted by supporters who hold a positive perception of parental abilities and when support is provided for both parent and child, rather than only the child. This type of support is more likely to be viewed positively by parents. Support is competence-inhibiting when it lacks collaboration (Tucker & Johnson, 1989). An understanding of parents' perception of the support they receive is essential for establishing if the support promotes their competence.

In line with this, the third, and current, phase of the research focuses on understanding the lived experiences of parents with ID. Similarly, in the public sector there is a greater acknowledgment of the importance of monitoring outcomes and quality of care from the

consumer perspective (Guinea, 2001). However, there is still limited understanding of the experiences of parents with ID (Theodore et al., 2018), and the perspectives of 'hard to reach' service users are often neglected (Chambers, Drinkwater, & Boath, 2003). In line with this phase of research, a review of parents' experiences of support, rather than a focus on outcomes, is indicated.

Moore (2013) conducted a review of parents with ID's experience of receiving formal support from professionals. The results highlighted that while the majority of parents with ID viewed professionals as part of their everyday lives, there was ambivalence around the usefulness of the support they received. However, the parents valued professionals providing practical and emotional support. The parents' experience of support was dictated by the attitude and approach of professionals; being reliable, trustworthy and good at listening were valued traits.

However, Moore's (2013) focus on formal support is limited. Parents with ID receive the majority of their support from family and other informal supporters, rather than professionals (Llewellyn, McConnell, Cant, & Westbrook, 1999). As both formal and informal support is associated with 'good enough' parenting (International Association for the Scientific Study of Intellectual Disabilities (IASSID), 2008; McGaw & Newman, 2005), a review of how parents experience both types of support is indicated. In addition, the Working Together with Parents Network (WTPN; 2016) highlight that good practice for supporting parents with ID requires a range of services and types of support.

In order to address these gaps in the evidence base, the current review explored how parents with ID experience formal and informal support for their parenting. Parenting support is defined as the accommodations parents with ID need to successfully parent their children (Lightfoot & LaLiberte, 2011). Formal support is provided by professionals, for example social workers, advocates and psychologists. Informal support is provided by a parents' social networks, including friends, family and neighbours. It is hoped a greater understanding of parents' qualitative experience will enable supporters to tailor their provision of support to the needs of this client group.

Method

Systematic literature search

To identify relevant studies, three electronic databases were systematically searched for articles published up until February 2019. These were PsycINFO, Web of Science Core Collection and psychARTICLES.

Three categories of search terms (Table 1) were used to explore each concept in the research question. The Boolean operator 'OR' was used within each concept, and the Boolean operator 'AND' was used to combine concepts. The terms were searched for anywhere in the text. Due to the relatively small number of studies exploring the area of interest, no limits were set on date of publication, but were limited to peer-reviewed journals accessible in English. The search terms were reviewed by a librarian with expertise in psychological systematic reviews and were thought to achieve an appropriate level of scope for answering the research question. In addition, the reference lists of included studies were hand-searched for papers to be included in the review and the researcher identified studies from her pre-existing knowledge of the literature.

Table 1

Search terms

Search category	Search terms used
Parents with ID	“parent* with mental retard*” OR “parent* with development* disabilit*” OR “parent* with intellectual* impair*” OR “parent* with mental* handicap*” OR "parent* with learning difficult*" OR "parent* with learning disabilit*" OR "parent*with intellectual difficult*" OR "parent* with intellectual disabilit*"
Parenting support	intervention OR support OR train* OR group* OR teach* OR guid* OR strateg* OR therap* OR network
Experience	qualitative OR perspective* OR view* OR experienc* OR interview* OR focus group*

Inclusion and exclusion criteria

To ensure rigour and high-quality review (Gough, Oliver, & Thomas, 2017) inclusion and exclusion criteria were applied to the search results to identify relevant studies. In comparison to Moore (2013) who only included studies in which parents had their children living at home, the current review defined parents as those who had their children living at home, or whose children had been removed from their care. This decision was taken as this inclusive definition of parenting is often used within the literature, and is the definition favoured by self-advocacy groups. In addition, parents who have had their children removed may still have contact with their children and often go on to have more children (Baum & Burns, 2007).

In line with the research question and the third phase of research which largely focusses on qualitative experiences (Llewellyn et al., 2008), the current review exclusively included qualitative studies.

Studies were identified as being relevant to the review if they met the following criteria:

- Peer-reviewed studies available in English
- Studies using qualitative methods or mixed designs with qualitative results reported separately
- Studies focusing on formal and / or informal parenting support for parents with ID
- Studies reporting parents with ID's experiences of parenting support

The criteria for being excluded from the review were:

- Studies in languages others than English
- Studies using only quantitative methods
- Studies only reporting the experiences of people other than parents with ID (for example, those reporting experiences of professionals, family members, adult children of parents with ID, people with ID who are not parents)
- Studies that only focused on topics that were related but not specific to the experience of parents with ID of receiving parenting support (for example, those that reported on support for mental health, those that reported on experience of parenting generally rather than parenting support, those reporting on the process of collecting interviews, those identifying types of support)

- Book chapters, book reviews, dissertation, editorials, opinion pieces, conferences presentations and abstracts which did not report a research study

Search results

As presented in Figure 1, the database searches identified 171 articles which were exported into Mendeley Reference Management Software. Forty-one duplicates were removed, leaving 130 articles. Nine additional articles were identified through searching the reference list of another systematic review which explored parents with ID's experiences of formal parenting support (Moore, 2013). The titles and abstracts of these 139 articles were reviewed in line with the exclusion criteria, and 108 were excluded. The remaining 31 articles were read in full, and of these, 12 met the inclusion criteria. The reference lists of these studies were reviewed, finding one additional study which met the inclusion criteria. Thus, 13 studies were included in the systematic review.

In order to ensure rigour and reduce bias, a second reviewer reviewed 25% of the full text articles ($n = 8$) in line with the inclusion and exclusion criteria. These were selected at random, using a random number generator. There was an 87.5% agreement between the two reviewers, and the inter-rater agreement was $\kappa = 0.71$, indicating a substantial level of agreement (Landis & Koch, 1977). Thus it was felt the second reviewer did not need to review the remaining articles. Discrepancy was resolved via discussion, resulting in one additional paper being included in the review.

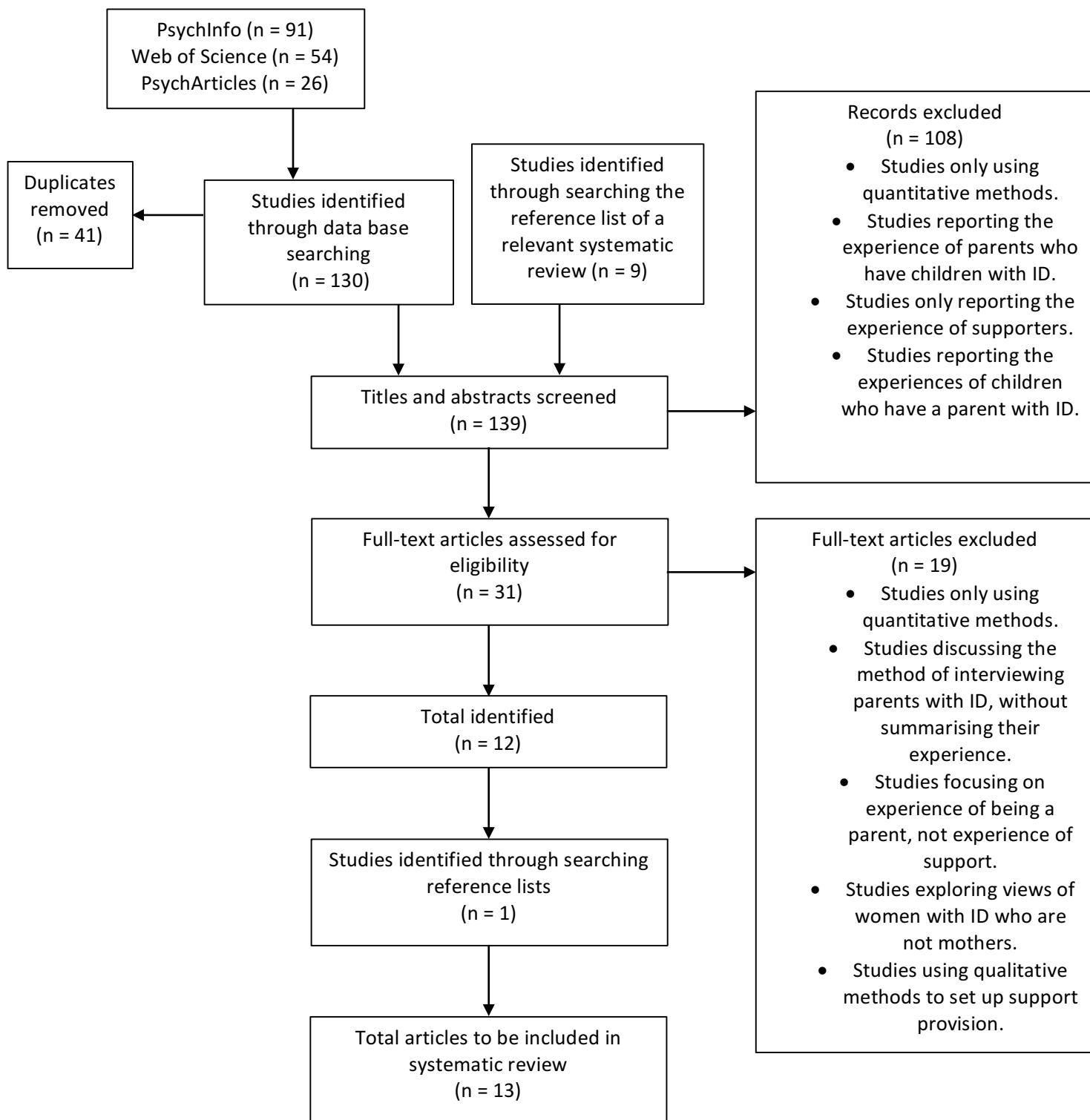


Figure 1. Flow chart of the search and study selection process (Moher, Liberati, Tetzlaff, & Altman, 2009).

Assessment of methodological quality

Quality of empirical research refers to the degree to which bias and error in design, data collection and data analysis are reduced (Khan, Kleijnen, & Antes 2003). Although the use of critical appraisal tools for qualitative research is debated (Atkins et al., 2008), their use prevents the inclusion of low quality studies which are likely to jeopardise the credibility of the review (Walsh & Downe, 2006).

The Critical Appraisal and Skills Programme (CASP; 2018) checklist for qualitative research was used to guide the assessment of the methodological quality of studies included in the review. The tool allows reviewers to reflect upon the relative rigour and relevance of qualitative research. When the studies used both qualitative and quantitative methodologies the CASP (2018) checklist was used to assess the qualitative section of the study only. Further, when studies explored the perspective of multiple informants, for example parents and advocates, the CASP (2018) checklist was only applied to the section reporting the experiences of parents, in line with the aim of the review.

The CASP (2018) checklist has been used in systematic reviews exploring experiences of people with ID (Corby, Taggart, & Cousins, 2015; McCann, Lee, & Brown, 2016) and is recommended for novice systematic reviewers (Singh, 2013). The CASP (2018) checklist has 10 criteria and thus each of the studies included in the review were given a score out of 10. Half points were given to studies when the criteria were partially met. A second reviewer rated the quality of 23% (n = 3) of the studies, selected using a random number generator.

In line with Fox, Dean and Whittlesea's (2017) methodology, a quality classification was assigned to each study. Studies which scored between 8.5 and 10 were identified as having few methodological flaws and being of good quality. Studies scoring between 5 and 8 had a moderate likelihood of flaws, and studies scoring between 0 and 4.5 were considered to have a high likelihood of methodological flaws, and thus were of poorer quality. These classifications were labelled A, B and C respectively.

However, employing the CASP (2018) checklist as a method of assessing the quality of the studies in the review had limitations. Evaluating the quality of the qualitative section of studies which use a mixed method design may give artificially low ratings of quality as strengths in one section of the research can compensate for limitations in the other (Heyvaert, Hannes, Maes, & Onghena, 2013). This limitation also applies when assessing the quality of the studies reporting on the experience of multiple respondents, such as parents and professionals. In addition, it has been suggested that the epistemological diversity in qualitative research impedes the meaningful appraisal of the quality of qualitative research (Carroll & Booth, 2015). Further, Toye, Seers and Barker (2017) suggest appraisal tools such as the CASP (2018) checklist do not measure the conceptual richness of a study, an important consideration in the quality of qualitative research.

Due to these limitations, and all studies being identified as being of at least moderate quality, none of the studies were excluded based on the ratings of their quality (Atkins et al., 2008). This is supported by Thomas and Harden (2008), who argue that there is no

accepted, or empirically tested, method for excluding qualitative studies from syntheses on the basis of their quality.

Data synthesis

Thematic synthesis was used as a method of integrating the findings of qualitative studies, and has been recommended for systematic reviews exploring perspectives and experiences (Thomas & Harden, 2008). Quotes from parents, and the authors' narrative description of parents' experiences, were extracted from each paper. This is in line with Thomas and Harden's (2008) suggestion that all the text tabled 'results' or 'findings' should be considered in the thematic synthesis. Similarly, Sandelowski (2004) argues findings of qualitative studies go beyond the reporting of raw data.

The first stage of the synthesis was line-by-line coding of the findings of the studies included in the review. These codes were then organised into related areas to generate descriptive themes. Finally, these were developed into analytic themes which enabled the researcher to go beyond the data in order to allow it to be understood in relation to the review question (Thomas & Harden, 2008).

Although, as discussed, no papers were excluded based on the quality assessment, after the thematic synthesis was complete, a sensitivity analysis was conducted in line with the post-hoc method described by Carroll and Booth (2015). The aim of the sensitivity analysis was to assess the effect on the synthesis of excluding findings from lower quality studies (Thomas & Harden, 2008). Carroll and Booth (2015) state that the quality threshold need not be

standardised. Instead, if a researcher deems a single methodological criterion to be the most significant confounder of findings, that alone can be used as the threshold for exclusion from the sensitivity analysis. As such, sensitivity analysis need not be based on an overall score for each study, which can mask the relative strengths and weaknesses of different studies. In line with this, the criteria of rigorous data analysis (CASP, 2018) was identified as the biggest confounder of quality. Two papers, Booth and Booth (2005) and MacIntyre and Stewart (2012), were identified as failing to adequately meet this criterion and as such the relative contribution these studies made to the final analytic themes was assessed. This showed in general, lower quality studies contributed comparatively less to the synthesis, compared to studies of higher quality. However, one descriptive theme, *“parents experiencing support as problem focused”*, was disproportionately influenced by the papers of lower quality and thus was removed from the final synthesis.

Findings

Quality assessment

The average quality rating for the thirteen studies was 8.04. Five of the studies were classified as A, signifying a low likelihood of methodological flaws. The remaining eight studies were classified as B, signifying a moderate chance of methodological flaws. None of the studies were classified as C. There were no discrepancies between the classifications assigned by the first and second reviewer. The classification for each study can be seen in Table 2. The overall scores and scores for each criterion can be seen in Appendix 1.

Commonly, studies lost points for a lack of clarity over whether the recruitment strategy was appropriate for the aims of the study, and a lack of rigorous data analysis. The studies also tended to have poor consideration of ethical issues. The most common reason studies lost points for quality was that they did not provide consideration of the relationship between participant and researcher.

Characteristics of included studies

Across the 13 studies included in the review, interview data was collected from 157 parents with ID. Other parents contributed to the observational data. Of these, 22 were specified as fathers and 99 as mothers. The parents' ages ranged from 20 to 61. The studies described a range of parenting support, including parenting groups (Booth & Booth, 1999; Gustavsson & Starke, 2017; Heinz & Grant, 2003), advocacy (MacIntyre & Stewart, 2012; Tarleton, 2008), and pre-and post-natal care (McGarry, Stenfert, Kroese & Cox, 2016; Wilson, McKenzie, Quayle & Murray, 2013). Other studies asked parents to reflect upon their general

experiences of receiving support for their parenting, for example from social networks (Llewellyn, 1995) and community ID teams or other specialised ID services (Booth & Booth, 2005; Starke, 2010; Tarleton & Porter, 2012; Tarleton & Ward, 2007; Theodore et al., 2018). Where stated, all studies included parents who had at least one child living at home with them. Eight studies (Booth & Booth, 1999; Booth & Booth, 2005; Gustavsson & Starke, 2017; Heinz & Grant, 2003; Tarleton, 2008; Tarleton & Porter, 2012; Theodore et al., 2018; Wilson et al., 2013) also included parents whose children had been removed from their care. In one study (McGarry et al., 2016), mothers were pregnant at the time of the interviews.

The majority of studies used proxy reports of ID, as is common in the literature (Brooker et al., 2015). For example, parents had accessed services provided for parents known to have an ID (Llewellyn, 1995; Heinz & Grant, 2003; McGarry et al, 2016; Tarleton, 2007; Tarleton & Ward, 2007; Wilson et al, 2013). One study used self-identification of ID (Gustavsson & Starke, 2017), and one study included an assessment of parents' ID (Tarleton & Porter, 2012). Five studies did not state how ID was established, but ID could be assumed through their contact with services (Booth & Booth, 1999; Booth & Booth, 2005; MacIntyre & Stewart, 2012; Starke, 2010; Theodore et al., 2018;).

Where reported, the studies were mainly conducted in community ID and social care settings in the UK. Two studies took place in Sweden (Gustavsson & Starke, 2017; Starke, 2010) and one in Canada (Heinz & Grant, 2003). The majority of studies only explored the experiences of parents with ID. One study was of an inclusive parenting group (Booth & Booth, 1999), but it is unclear if the parents without ID were also interviewed. Three studies

also included the experiences of professionals working with parents with ID, namely doula (McGarry et al., 2016), advocates (MacIntyre & Stewart, 2012) and group facilitators (Heinz & Grant, 2003). The experiences of these different groups were reported separately and not included in this thematic synthesis.

Qualitative data was collected using interviews, either individual or group, in all of the studies. Three studies also used observational methods and field notes (Gustavsson & Starke, 2017; Heinz & Grant, 2003; Llewellyn, 1995). One study used survey data in addition to interviews (MacIntyre & Stewart, 2012), although this concerned the perspectives of professionals and not parents. This data was analysed using a range of qualitative methods. Grounded theory techniques were used most commonly, reported in four of the studies (Gustavsson & Starke, 2017; Llewellyn, 1995; Tarleton, 2008; Tarleton & Ward, 2007). Two studies used Interpretative Phenomenological Analysis (IPA) (McGarry et al., 2016, Wilson et al., 2013), and two used thematic analysis (Tarleton & Porter, 2012; Theodore et al., 2018). Other methods such as textual analysis and content analysis were also used.

Characteristics of the included studies are shown in Table 2. Not all of the studies provided explicit data, for example participants' ages.

Table 2
Study characteristics

	Authors	Title	Country	Aim	Participants	Care of children	ID established	Parenting support	Data collection	Analysis	CASP
1	Llewellyn (1995)	Relationships and social support: Views of parents with mental retardation / intellectual disability.	Not stated.	To investigate how parents with ID view relationships and support provided in relation to their parenting.	Six couples. In four of the couples, both had an ID. Age 28-39.	Parents were those who were primarily responsible for caring for their children.	Parents had used health or welfare services which had identified them as having an ID.	Assistance, advice, or interventions provided by the people parents regard as being part of their social networks (e.g. family members, friends, neighbours and professionals).	In depth and unstructured interviews and field notes from observations of parents.	Grounded Theory.	A

2	Booth and Booth (1999)	Parents Together: action research and advocacy support for parents with learning difficulties.	UK.	To provide an account of an action research project of a parenting group. To understand how the group impacted upon discriminatory practice and parents' esteem.	23 mothers and 3 fathers with ID. 2 mothers and 10 fathers without ID.	Parents whose children lived with them, or were in care.	Not stated.	A parenting support group, <i>Parents Together</i> , which aimed to empower parents, enhance self-esteem, increase social networks to help parents better care for their children. The group focused on reducing the pressures on parents, rather than developing parenting skills. The group was facilitated by support workers.	Interviews.	Profile approach.	B
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3	Heinz and Grant (2003)	A process evaluation of a parenting group for parents with intellectual disabilities.	Canada.	To evaluate a new and specialist parenting programme and to collect information that could improve the programme. To describe in detail, the components and goals of the programme.	4 programme facilitators. 34 parents who attended the programme. 3 parents were interviewed. Age 20-57.	Parents whose children lived with them, or were in care.	Parents identified as having a learning disability in their social care referral.	A group parenting programme, <i>Parents Forever</i> , which helped parents to experience healthy relationship with their children and learn parenting skills. The group addressed the needs and topics suggested by parents. The programme was facilitated by staff from health and social care professions.	Participant-observer approach, using observation forms, 'how do you feel?' sheets and small group interviews. Facilitator debriefing form also used.	Content analysis.	B
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4	Booth and Booth (2005)	Parents with learning difficulties in the child protection system: Experiences and perspectives.	England.	To provide an experiential account of care proceedings from the perspective of parents with ID.	18 mothers and 4 fathers with ID.	Parents with children living with them, or in care.	Not stated. Assumed through recruitment from health, social services and advocacy schemes .	Support from social workers.	Interviews.	Not stated.	B
5	Tarleton and Ward (2007)	'Parenting with support': The views and experiences of parents with intellectual disabilities.	England, Scotland and Wales.	To understand positive practices in supporting parents with ID in the UK, from the perspective of parents.	25 mothers and 5 fathers with ID. Age 20-50.	Parents with at least one child living with them.	ID established as a criterion for accessing community ID teams.	Support provided by community ID teams to help them fulfil their parenting responsibilities . All parents had had contact with social care.	Individual and group interviews.	Established qualitative analysis procedures drawing on methods from grounded theory.	B

6	Tarleton (2008)	Specialist advocacy services for parents with learning disabilities involved in child protection proceedings.	England.	To explore whether parents with ID benefit from advocacy support. To assess whether professional practice within the local area had been affected by advocacy for parents with ID.	14 parents with ID.	Parents with children living with them, or in care.	ID established in parents' contact with child protection.	Advocacy support for parents with ID during child protection proceedings.	Interviews.	Established qualitative analysis procedures drawing on methods from grounded theory.	B
7	Starke (2010)	Encounters with professionals : views and experiences of mothers with intellectual disability.	Sweden.	To explore the views and experiences of mothers with ID regarding their interactions with care and support practitioners.	7 mothers with ID. Age 24-42.	Parents living with at least one child.	Not stated. Assumed through contact with adult rehabilitation centres.	Professional support offered by adult rehabilitation centres and social services, providing financial and practical support.	Interviews.	Textual analysis.	A

8	MacIntyre and Stewart (2012)	For the record: the lived experience of parents with a learning disability – a pilot study examining the Scottish perspective.	Scotland	To identify the needs of parents with ID in Scotland, and explore the role of advocacy in assisting parents with ID to have their needs met.	5 mothers with ID. Age 24-45. 5 advocates of parents with ID. Professional s working in social work, health and voluntary organisation s which support parents with ID.	Not stated.	Not stated. Assumed through contact with advocacy organisations	Advocacy support following child protection proceedings.	Mixed methods. In-depth interviews with parents and advocates. Survey questionnaire with other professionals	Inductive and deductive approach.	B
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9	Tarleton and Porter (2012)	Crossing no man's land: A specialist support service for parents with learning disabilities.	England.	To gain an increased understanding of the effectiveness of the Valuing Parents Support Service (VPSS) for parents with ID and their children.	12 parents who had been supported by the service for a minimum of 6 months.	Parents with children living with them, or in care.	Cognitive assessments indicating mild or borderline ID.	VPSS provided specialised support for parents with ID, such as practical support and teaching parenting skills. The service was delivered by social workers and family support workers.	Focus groups.	Thematic analysis.	B
10	Wilson, McKenzie, Quayle and Murray (2013)	The postnatal support needs of mothers with an intellectual disability.	Scotland	To explore the postnatal care experiences of mothers with ID.	6 mothers with mild ID. Age 20-55.	Parents with children living with them, or in care.	ID established as a criterion for accessing community ID teams.	Post-natal care.	Semi structured interviews.	IPA.	A

11	McGarry, Stenfert Kroese and Cox (2016)	How do women with an intellectual disability experience the support of a doula during their pregnancy, childbirth and after the birth of their child?	England.	To understand the experiences of parents with ID who experience doula support during pregnancy, birth and in the post-natal period. To understand the experience of doulas who provide support to parents with ID.	4 mothers with ID. Age 20s-30s 3 doulas who supported women with ID.	Pregnant during the research.	ID established as a criterion for accessing local ID services.	Support from trained doulas, with additional training in working with others with ID.	Semi-structured interviews with mothers before and after birth. Semi-structured interviews with doulas at the end of the post-natal period (6-8 weeks after birth).	IPA.	A
12	Gustavsson and Starke (2017)	Groups for parents with intellectual disabilities: a qualitative analysis of experiences.	Sweden.	To understand what the social contacts with parents and social workers in a group for parents with ID mean to parents.	Seven parents who attended a parenting group.	Parents with children living with them, or in care.	Diagnosis or self-definition of ID.	A group for parents with ID, giving them the opportunity to discuss parenting issues and initiate social contacts. Parenting	Field notes taken during participant observation and interviews.	Techniques inspired by grounded theory interpreted within a social capital and symbolic interactionism framework.	B

								education was not provided.			
13	Theodore et al. (2018)	`We want to be parents like everybody else': stories of parents with learning disabilities.	England.	To collect stories of a group of parents with ID. To impact on policy, reduce stigma, and alter misconceptions	5 mothers and 4 fathers with ID. Age 31-61.	Parents with children living with them, or in care.	Not stated. Assumed through self-identification and contact with self-advocacy groups.	Support from ID services, including health and social care professionals.	Semi-structured interviews.	Thematic analysis.	A

Data synthesis

The stages of analysis outlined above led to the development of two themes and five subthemes. Parenting support for parents with ID was experienced both positively and negatively, and this was dictated by the experience of the helping relationship and the nature of the support provided. In addition, exposure to preconceptions of others was detrimental to the experience of being supported. The themes and subthemes, and the numbers of papers contributing to each theme, can be seen in Table 3.

Table 3

Themes and subthemes developed by the thematic synthesis

Theme	Subtheme	Number of papers contributing to each theme
A negative experience of support	Experiencing the preconceptions of others	7
	Experiencing the helping relationship negatively	10
	Experiencing elements of support as unhelpful	7
A positive experience of support	Experiencing the helping relationship positively	13
	Experiencing elements of support as helpful	13

The specific papers contributing to each subtheme can be seen in Appendix 2.

A negative experience of support.

Experiencing the preconceptions of others.

Some parents, reported in seven of the papers, experienced others in their support networks as holding negative preconceptions about their parenting ability. Parents felt exposed to a presumption of incompetence, by both professional, most commonly from the child protection system, and informal supporters. It is notable that parents reported negative preconceptions even within services specially designed for parents with ID.

“They [professionals] think oh because a girl’s got moderate learning problems they think can’t look after a baby you know.” (McGarry et al., 2016, p.26)

“Phone calls from [father of the child] asking me how I could have done this to their youngest son [...] doubts that I’ll never be able to make it.” (Starke, 2010, p.14)

Parents felt supporters holding assumptions about their parenting abilities led to heavy scrutiny from both formal and informal supporters, and the support often felt intrusive. Parents felt this was above and beyond the scrutiny experienced by parents without ID. Many parents felt their supporters had an agenda to remove their children from their care, rather than to support them in their parenting. This experience led some parents to feel angry, and some wanted to disengage from the support provided. Parents disengaging from support reinforced the belief held by supporters that they were incompetent, thus increasing the negative experience of support.

“They [professionals] were taking notes to feed back to social work on how I was getting on looking after the baby on my own [...] there in my face all the time, and I couldnae cope with it.” (Wilson et al., 2013, p. 596)

“They [social workers] hear what they want to hear, don’t listen to your side. They don’t understand what you are saying. They only hear what they want to. They are only interested in taking your kids.” (Tarleton & Ward, 2007, p.199)

“Many of the parents had had previous, negative, interactions with staff from these teams, which had resulted in their disengagement from services.” (Tarleton & Ward, 2007 p. 198)

Experiencing the helping relationship negatively.

In 10 of the papers, there were reports that the relationship with supporters, both formal and informal, was experienced negatively, likely to be influenced by the presumption of incompetence. There were several factors within the relationship which contributed to this. Parents experienced their supporters as poor listeners, for example social workers were often described as ignoring parents’ knowledge of their own children. Supporters not specialised in supporting parents with ID, for example doctors, were also described as poor listeners, as were family members. Parents felt frustrated and isolated by the experience of not being listened to.

“I says you have to leave her herself to wake up and I says you can try her, and you’ll find out, so I woke her up and tried but she would nae take that bottle ‘that’s what I tell you, you

got to leave her and let her wake up herself', they [professionals] tried to force us. I says 'dinnae force me'." (Wilson et al. 2013, p.595)

"Before I always had to go to my family doctor with my problems, and that's not always great. Doctors are too busy and don't give you the time, they aren't interested in listening [...] with the doctor I have, he's one to push you out the door if you try to talk about a problem." (Heinz & Grant, 2003, p.271)

"Me, I didn't feel I had anyone to talk to. My partner wouldn't listen." (Heinz & Grant, 2003, p.271)

Supporters who did not listen to parents often had a poor understanding of parents' knowledge, strengths and needs. As a result, they took a directive, rather than collaborative, approach in the supporting relationship. For some parents, this led them to not follow the advice they were given.

"I didn't like that [professional's name] cos she were a bit clever all the time, you've got to do this, you've got to do that [...] all she did was just sit and talk, talk, talk. Why don't you do this? Why don't you do that? Take him here, take him there." (Booth & Booth, 2005, p.116)

"They [professionals] were telling me stuff to dae and how to dae it and I was getting quite snappy wi them, cause I was like, have you got kids of your own no, well don't tell me what to dae then." (Wilson et al., 2013, p.595)

“Mum said he could only go as far as the letter box, that he’s not allowed out. But I let him out yesterday onto the footpath.” (Llewellyn, 1995, p. 357)

In addition to being directive, both professional and family supporters were also experienced as being critical. Parents’ limitations were highlighted and their strengths overlooked, and this had a negative emotional impact on parents. As a response, some parents disengaged from support.

“He [relative] tells me, you shouldn’t have more children, and sometimes that makes you feel depressed ... you’re not a good mother.” (Starke, 2010, p.15)

“She [professional] went ‘you never done that right! You shouldnae have left her on the floor’ I was like ‘She aint going to move for crying oot loud’ and I chucked her oot my hoose.”
(Wilson et al. 2013, p.596)

“War between myself and the social worker [...] they go out of their way to say how crap you are.” (Tarleton, 2008, p.136)

“I thought it [parenting being criticised] was so humiliating. I got so angry.” (Starke, 2010, p.13)

It is notable that in three of the papers, parents did not report a negative experience of the helping relationship. These papers reported on specialised and flexible parenting support

services for parents with ID and doulas who had been specifically trained to support parents with ID.

Experiencing elements of support as unhelpful.

In addition to the relational aspect of support being experienced negatively, in seven of the papers there were also some elements of the support itself which parents experienced as unhelpful. This tended to occur when less specialised support was provided. In some instances, the support did not mirror parents' own identified needs, and sometimes focused on skills parents felt they already possessed. On other occasions, parents felt they did not get the support that had been agreed, and support they did receive was experienced as intangible. It was felt children's needs were prioritised, and parents' own needs were neglected. In the home, partners were often described as lazy or providing inadequate support.

"I don't see that [support from social workers] as a support, cos that's just normal chitchat... I don't think that's support at all." (Wilson et al., 2013, p.595)

"They [professionals] were teaching me stuff I could already do like how to feed my son... and they made a report to the social worker to say [I'm] not fully taking part in these courses... I told her... they're telling me stuff I already know, I don't need those courses, they're not right for me." (Theodore et al., 2018, p.190)

“He (her partner) wasnae helping us ken he was just sitting watching telly and everything. He wouldnae feed the bairn or change the bairn, he would just sit and watch sport all the time.” (Wilson et al., 2013, p.595)

In addition, when the information provided during the support was inaccessible, parents experienced the support as unhelpful.

“Mothers did not feel that they received sufficient information or that this information was easy to comprehend.” (Starke, 2010, p.12-13)

“Their [parents] view was that very little adjustment had been made to make meetings accessible.” (MacIntyre & Stewart, 2012, p.10)

A positive experience of support.

However, all the papers reported some parents experienced their relationship with supporters and the nature of the support positively. Parents reported positive experiences from a broad range of supporters, including professionals offering both generic and specialised support, and informal supporters.

Experiencing the helping relationship positively.

Some parents described their relationship with their supporters as a positive one. Relationships with professionals were experienced as close, supportive and kind. This was achieved when supporters were consistent in their approach and readily available. This type of relationship was valued and improved the experience of being supported. Parents also

valued their relationships with other parents. These were experienced as sympathetic, and a main motivator for attending parenting groups.

“The kindness they [professionals] show.” (Tarleton & Porter, 2012, p.239)

“They [doulas] were always there, always one of them there and they are fantastic, all through the week supporting us [...] they’re like family now to us, she’s like a mum I never had.” (McGarry et al., 2016, p.28)

“If you have a puzzled look on your face, they’re [group facilitators] right there, they’re so concerned. Week after week they ask about your problem.” (Heinz & Grant, 2003, p.268)

While some parents felt they were not listened to, others reported feeling listened to and understood by their professional supporters. Advocates were most likely to be reported as good listeners, and they encouraged other members of the system to also listen to parents. Other parents in parenting groups were also reported to be good at listening, and they were able to develop a shared understanding. This helped parents to realise other parents experienced difficulties too, and they felt less alone. Notably, family members were rarely reported to be good listeners.

“It was nice that they [professionals] actually did that and listened to me, let me get it all out basically.” (Wilson et al., 2013, p.594)

“He [social worker] sat and listened and if I was upset he was a really good listener.” (Booth & Booth, 2005, p.116)

“Everybody’s been there to listen. I enjoy listening to other parents and what they’ve been through.” (Booth & Booth, 1999, p.472)

In addition to being listened to, some parents felt supporters from a range of professional and informal backgrounds believed them and didn’t judge them. This helped parents to experience supporters as trusting and trustworthy, and this was demonstrated by supporters taking a non-judgmental stance and being open with parents. Being believed was seen as a factor which distinguishes good supporters from bad ones.

“He’s [advocate] the only one I trust... I told him he is the only one I trust... I don’t trust anyone else I trust him.” (MacIntyre & Stewart, 2012, p12)

“In all those eight social workers that my children have had there’s been one nice one... she was the one believed in me and got me to keep my children. All the rest didn’t, you know, believe in me.” (Theodore et al. 2018, p.190-191)

“[Local organization] helped me and Kylie, not judging us, helping us with things to do with April [baby].” (Tarleton & Ward, 2007, p.197)

A shared understanding and trust promoted a collaborative stance, which was experienced positively by parents. Parents described supporters being alongside them, guiding them

rather than directing them. Partners were described as providing complementary support, which was valued.

“They [group facilitators] ask you how you would deal with it and they say they will stand by you.” (Heinz & Grant, 2003, p.271)

“It was good to have someone [an advocate] on my side.” (Booth & Booth, 1999, p.468)

“Reciprocity was demonstrated [by partners] by provision of physical help, support for the other person’s views or wishes, and moral support, [...] shared decision making.” (Llewellyn, 1995, p.356)

A positive relationship, one where supporters listen, take a non-judgemental and collaborative stance, were empowering and increased parents’ confidence. As a result, some parents reported needing less support.

“I’m not as shy now, I can em, like if I don’t know someone, I’ve got more confidence to actually speak to them rather than shy away from that person and try and engage wi’ them. Whereas before, if I didnae ken someone I wouldnae talk to them and I would sit in the corner and things.” (Wilson et al., 2003, p.594)

“I still have Barbara [community nurse] but not as much now because I’m doing alright.”
(Tarleton & Ward, 2007, p.198)

Experiencing elements of support as helpful.

Parents described elements of support that were experienced positively and helped them to achieve change. Adaptations for their learning needs, such as using simple language, easy read materials and drawing tasks, were experienced positively. Parents also felt their supporters, mostly advocates, translated information for them in meetings, making them more accessible.

“That’s how we find things a lot better, practical with easy read and writing to help with mumble jumble [jargon].” (McGarry et al., 2016, p.27)

“She [advocate] explains to me what I don’t understand, what Social Services are talking about. If I didn’t understand what questions were she’d repeat it and explain it.” (Booth & Booth, 1999, p.468)

“I was finding it hard to understand cause of my learning disability, so he [professional] drew on a piece of paper.” (Wilson et al., 2013, p.596)

Support which focused on parenting skills was helpful, for example, an increased understanding about appropriate boundaries. Parent skills were often taught through modelling, which was experienced as less directive than being told what to do, and thus promoted parents’ competence. Parents also valued support around practical tasks, such as managing debt, housing, and what to buy for their children. Learning new skills was

experienced most positively when parents received positive feedback, which contrasted with the broader narrative around parenting limitations and challenges.

“We’re getting there. She [community nurse] helps me know how to say no. Different ways of saying no... It’s helping a lot I say ‘mummy is busy at the moment, later’.” (Tarleton & Ward, 2007, p.197)

“Cause if you ever asked a question, they [professionals] would tell you what to do and show you what to do but that was it. They wouldnae say you’re doing wrong or that.” (Wilson et al., 2013, p.594)

“I got in so much debt I was getting stressed out and everything... they [community intellectual disabilities team] take all the letters off me now, they keep them in a file... took me to welfare rights.” (Tarleton & Ward, 2007, p. 197)

“I think it’s important, as a mother, I mean to get commended a bit like that, you know. And it’s important to get - when it gets really, really tough, it’s so great, so nice [...] to get a bit of positive feedback.” (Starke, 2010, p.16)

Supporters, both professional and family members, helped parents to manage a range of emotions, including sadness, anger and anxiety, and this element of support was experienced positively. These emotions were related to difficulties in parenting and frustrations engaging with a system which was often inaccessible to them.

"The [parenting] group helped me as it got me talking about my anger." (Booth & Booth, 1999, p.472)

"Before going to meetings she [advocate] tells you not to be aggressive, not to lose it. If I am gonna get angry, she tells them I need time out, I need a break. She can tell when I am getting angry, gives you the look and says 'Calm down, cool down'." (Tarleton, 2008, p.137)

"When I get low, I get emotional very easily, he helps me out of it, he brightens me up every time I see him... I feel like ending it all, the advocate said don't do that." (Tarleton, 2008, p.138)

Support was experienced positively when it reduced social isolation. Many of the parents described how, if not supported, they would spend a lot of their time on their own. Both professionals, family members and other parents were seen as sources of connection.

"Get my fill of talk and not go around alone at home." (Gustavsson & Starke, 2017, p.643)

"It was good to talk to someone [...] we got on great with her [advocate] and had some laughs. She was someone to talk to. She was company during the day [...] I was always stuck in before." (Booth & Booth, 1999, p.468)

"Otherwise I'm stuck indoors, out in the sticks." (Tarleton & Porter, 2012, p.239)

Discussion

The review set out to increase understanding of how parents with ID experience support for their parenting, both from professional and informal supporters. The results of the review found parents face presumptions of incompetence and as a result their parenting is scrutinised. The relationship with the supporters was a key element of parents' experience of support. There were elements of the relationship that were experienced positively and led parents to feel empowered. However, relationships with supporters were also experienced as disempowering, for example when supporters were critical, directive and poor at listening. There were also elements of the support itself which impacted on the experience of it. Elements that were experienced as helpful include appropriate adaptations for learning needs, the teaching of parenting and practical skills, meeting emotional needs and reducing social isolation. Support was experienced as unhelpful when it did not match parents' own perception of their needs and was inaccessible.

The results are discussed in line with Tucker and Johnson's (1989) model of competence promoting and competence inhibiting parental support for parents with ID. They argue that while parenting support often aims to promote competency and wellbeing, this is not always achieved, and support can potentially inhibit parents' performance. This conceptualisation helps to explain why parenting support is at times experienced as helpful, and at others unhelpful.

Preconceptions of parenting competence.

Support, intended to be helpful, can be experienced negatively when offered in a context which presumes incompetence (Tucker & Johnson, 1989). The review found parents often perceived supporters as judging them as incompetent, and as a result scrutinising their parenting. This presumption of parenting incompetence is echoed in the literature (Gould & Dodd, 2014). Parents were fearful their child would be removed, which, unfortunately, is a common occurrence for parents with ID (Booth et al., 2004).

Although parents with ID do often struggle with the demands of parenting (Emerson & Brigham, 2014), the evidence suggests the link between parental IQ and parenting ability is mediated by contextual factors, such as poor housing, single parenthood, social isolation, mental health difficulties and histories of abuse (Schuengel et al., 2017). Therefore, the parenting difficulties experienced by parents with ID cannot be said to be causally related to cognitive ability (Llewellyn & Hindmarsh, 2015). As such, while parents commonly experience a presumption of parenting incompetence, this presumption is not necessarily supported by empirical evidence.

Parents' experience of being presumed incompetent led to feelings of anger and frustration, and disengagement from support. Parental non-compliance with support is often seen by professionals as an indication that parenting will not improve (Booth & Booth, 2004), often resulting in children being removed. Therefore, a presumption of incompetence, as experienced by parents, perpetuates the likelihood of parents losing their children. This is

similar to the self-fulfilling prophecy suggested by Tucker and Johnson (1989): parents who experience support as competency inhibiting are likely to have poorer parenting outcomes.

Relationship with supporters.

The results suggest the relationship with the supporter was also a key determinant in whether the support was experienced as promoting or inhibiting competence, in line with Tucker and Johnson's (1989) conceptualisation and the evidence base (for example, Jamieson, Theodore & Raczka, 2016). The relationship was experienced positively when parents were listened to, understood, respected, and when support was collaborative. A relationship of this type is in line with government commitments to promote empowerment for people with ID (DoH, 2001). These supportive relationships were formed most easily with advocates and doulas. A good relationship with supporters is also a protective factor for children. Meppelder, Hodes, Kef and Schuengel (2014) found that parents with ID who had good alliances with their supporters are more likely to seek support quickly, which decreased the likelihood of abuse and neglect.

However, elements of the relationship were also experienced as disempowering. These included not being listened to, being criticised, and non-collaborative support. Parents often experienced supporters as intrusive, encroaching on their independence. This kind of relationship tended to be with social workers and supporters without special training in supporting parents with ID, such as doctors. There was a sense parents were left feeling vulnerable, as their independence was undermined, which is known to inhibit competence (Tucker & Johnson, 1989). However, some parents reported positive relationships with

social workers and therefore there were individual differences, such as being a good listener, that influenced the helping relationship, rather than only the role or job title of the supporter.

It is of note that many parents with ID grew up in care themselves or were exposed to adverse childhood experiences such as maltreatment (Granqvist, Forslund, Fransson, Springer & Lindberg, 2014; Vervoort-Schel et al., 2018). The power of the therapeutic relationship for people who have experienced early traumatic relationships is well documented (Lemma, 2010), and thus people who support parents with ID should strive to provide a containing and therapeutic relationship.

The nature of support.

Tucker and Johnson (1989) argue the nature of the support determines whether it promotes or inhibits parents' competence. The review highlighted several elements of the support which were experienced positively. Parents valued support which made adaptations for their learning needs and limitations, in line with McGaw and Newman's (2005) recommendations. Parents also valued learning parenting and practical skills. Modelling was identified as an effective method of learning, and was experienced as promoting competence, compared to more directive forms of teaching. Modelling has been identified as a useful element in parenting interventions with parents with ID (Ward & Tarleton, 2007). Parents also valued support when it included positive reinforcement of their parenting skills, as recommended by McGaw & Newman (2005).

Parents valued support that addressed their emotional needs. Although often ignored by supporters, people with ID have rich emotional lives (Arthur, 2003) and supporters should help parents with ID to receive the right emotional support for themselves and their families (DoH, 2009). Parents experienced support positively when it helped to reduce their social isolation. Parents with ID are often isolated (Schuengel et al., 2017) and social isolation is a factor known to exacerbate psychological difficulties for people with ID (Bates & Davis, 2004). Therefore, it could be hypothesised that the reduction in isolation facilitated by supporters could improve the mental health of parents with ID who access support.

However, other elements of the support were experienced as inhibiting parents' competence. Parents felt that while substantial support was offered, it was not in line with their own identified needs and was often experienced as inadequate (Tucker & Johnson 1989). Information was often inaccessible, meaning parents felt isolated from the support offered to them. Parents also often felt their child's needs were prioritised, and their own needs neglected. While policy states the children's needs are paramount (Children Act, 1989), support that is not responsive to parents' needs is experienced as competence inhibiting (Tucker & Johnson, 1989), and thus unhelpful.

In summary, the findings of the review show parenting support has the potential to promote parenting competence and increase the likelihood of positive outcomes, but also the potential to limit parents' competence and success. While the relationship between competence promoting support and parenting competence is not causal, competence

promoting support maximises the chances of parental success and thus should be employed where possible (Tucker & Johnson, 1989).

Clinical implications

Although the current review focuses on the experience of support, rather than outcomes, Tucker and Johnson (1989) suggest that support that is experienced as promoting parenting competence leads to better outcomes for both parent and child. Therefore, supporters should strive to improve the experience of support for parents with ID, and there are several ways this can be achieved.

The results suggest the experience of a presumption of incompetence increases the likelihood of children being removed into care. In line with the Children Act (1989), children should remain with their birth parents where possible. Therefore, supporters should strive to demonstrate to parents that they presume they have the ability to be effective and successful parents. This can be achieved by teaching parents skills to help them become self-reliant and feel in control, and highlighting parenting successes. Supporters should be available to provide support when problems occur, while promoting parents' independence and encouraging them to overcome their own difficulties (Tucker & Johnson, 1989).

Supporters should be mindful that parents with ID are likely to have been exposed to problem saturated narratives and defined by their limitations for the majority of their lives (Dawes, 2011). In order to challenge this presumption of incompetence, an alternative, strengths based narrative requires attention in order to be accepted into parents' lives, and

supporters should focus on stories of competency, as opposed to disability (Baum, 2007). Supporters should therefore work to support parents who disengage, and understand this as a response to social narratives around disability, rather than necessarily a demonstration of parenting limitations. In addition, services should provide supporters with opportunities to reflect upon their own narratives around disability, and foster a narrative of competency and ability.

However, providing competence promoting support is time consuming and thus is executed best when supporters are themselves under low-strain (Tucker & Johnson, 1989). In times of austerity and increasing pressure on learning disability services (McInnis, Hills, & Chapman, 2012), support for supporters is often overlooked. Therefore, a clinical implication is that services who support parents with ID should provide appropriate supervision for professionals, and informal supporters should be provided with support and respite in order to be able to effectively support parents with ID.

Certain aspects of support were experienced negatively and thus support providers should adapt the delivery of support to minimise these factors. Parents often felt their needs were not met. A thorough assessment, focusing on parenting skills and strengths should be undertaken to understand where parents are already functioning effectively, and where they need help (British Psychological Society; BPS, 2011). Worryingly, many parents with ID report not having had an assessment of their parenting needs (Booth & Booth, 2005) and thus this should be incorporated into services which support parents with ID. However, parents with ID are often over assessed (McGaw & Newman, 2005) and assessments can be

experienced as undermining competence (Booth & Booth, 2005). Therefore, services should follow good practice guidelines when assessing parents with ID (WTPN, 2016).

Some parents discussed the accessibility of the information provided by supporters, and this was associated with whether support was experienced as helpful. In line with standard practice for working with people with ID, supporters should use simple language and visual stimuli to aid understanding (WTPN, 2016; McGaw, 2000). These adaptations have been found to be helpful in therapeutic interventions with people with ID (Whitehouse, Tudway, Look, & Kroese, 2006). Resources should be meaningful to the individual parent, and should match their level of understanding and preferred approach of communication (McGaw & Newman, 2005).

Reducing social isolation is experienced positively by parents with ID, and has the potential to improve their mental health (Bates & Davis, 2004) and develop their parenting skills (Gustavsson, & Starke, 2017). The reviewed studies highlighted parents with ID benefited from increased contact with each other as this reduced isolation and provided parents with opportunities to share knowledge and experiences. Therefore, services should strive to help parents to make social connections, for example offering support in a group format.

In summary, the findings broadly support the application of best practice guidelines for supporting families with a parent with an ID (WTPN, 2016). There are concerns these principles are not routinely implemented across the UK (Rosli & Rossi, 2014; Theodore et al.,

2018) and as such the current review serves as a reminder of the importance of adhering to such guidelines.

Methodological strengths and limitations of the included studies

In general, the included studies were of moderate quality. There were several strengths in the methodologies of the included studies, for example all studies gave a clear statement of their aims and findings. The majority of the studies gave a clear rationale for the use of a qualitative method. However, there were several methodological limitations across the studies which impact on the quality of the thematic synthesis. The majority of the studies failed to adequately consider the relationship between participant and researcher.

Consideration of a researcher's own values and assumptions related to the research question is a key element of high quality qualitative literature as it helps the reader to interpret the researcher's understanding of the data (Elliott, Fischer, & Rennie, 1999).

However, limited reflection on researcher reflexivity may be due to restricted word counts, rather than because reflections did not occur (Walsh & Downe, 2006). This highlights the limitations of using a checklist approach to assess the quality of qualitative research. The data analysis was often not described in ways that made it possible to assess if it was sufficiently rigorous. It was often unclear how themes were derived from the data, or the extent to which contradictory data was taken into account.

Several empirical papers have explored best practice for interviewing parents with ID in order to ensure high quality data is collected (for example, Booth & Booth, 1994). However, in the majority of papers included in the review, it is unclear if there was consideration of these factors. For example, Booth and Booth (1994) suggest cognitive limitations, such as

memory difficulties, inherent to people with ID can be a limiting factor in data collection. Consistency checks, such as interviewing informants, can be helpful (for example, Booth & Booth, 1994). However, very few included papers made reference to these guidelines, perhaps resulting in lower quality data collection.

A limitation of the samples in studies included in the review is that mothers were over represented compared to fathers, limiting the generalisation of the findings. Similarly, all studies took place in a western context and therefore the ability to generalise to other societies is limited. This is of particular relevance as support provisions for people with ID in developing countries is limited (Eleweke, & Rodda, 2002). As it is estimated the majority of people with ID live in developing countries (Eleweke, & Rodda, 2002), further research could explore the experience of parenting support for this client group across the developing world.

A final limitation across the studies is that the ethical review process was not always clear. This is of particular concern as people with ID may be vulnerable research participants (Booth & Booth, 1994). Booth and Booth (1994) suggest special consideration should be paid to the consent process and right to withdraw. It is not clear if this was achieved in some of the included studies.

Strengths and limitations of the review

A strength of the current review is its ability to capture the voice of parents with ID, who are often silenced in research. People with ID are the experts on their own experience (Booth & Booth, 1994), and this is acknowledged in the reviewed papers.

One potential limitation of the review is the possibility that not all relevant literature was located, for example unpublished literature was not searched for. The decision to only include peer reviewed papers was taken in an attempt to ensure a review of high quality research. However, it is possible that high quality research, which has not been published, exists. This could be due to a number of factors such as publication bias (Petticrew et al., 2008), and researchers' inclination to prepare a research study for publication. In addition, many qualitative articles have unclear titles and abstracts (Jones, 2004). While a conservative approach was taken during screening, it is plausible some relevant studies were screened out. Therefore, relevant research may not have been included which impacts on the rigour of the review.

Although this is a potential limitation, Thomas and Harden (2008) argue it is not necessary to locate every relevant study in a qualitative systematic review. The aim of the review is interpretive explanation rather than prediction and thus the sample of included papers is purposive rather than exhaustive. While the current review may not have located every paper relevant to the research question, a systematic methodology of searching was employed, including supplementing the results of the electronic searches by hand searching

reference lists of relevant papers. Therefore, there is confidence in the conclusion that a good proportion of high-quality and relevant papers were included in the review.

In order to ensure rigour in the review, two independent reviewers should be involved when deciding if studies meet the inclusion and exclusion criteria and assessing the quality of included studies (Wright, Brand, Dunn, & Spindler, 2007). In the present study, this was not achieved and thus is a limitation. In an attempt to overcome this limitation, second reviewers were used for a proportion of studies. This process highlighted there was substantial agreement between reviewers, and thus it was felt a second reviewer was not necessary to screen every paper. The second reviewer provided an adequate level of rigour for the review.

It could be argued that the range of different types of support in the included studies was a limitation of the review as it made conclusions difficult to draw. This decision was taken for several reasons. Firstly, there is limited evidence exploring parents with ID's experiences of parenting support and to focus on a single type of support, such as advocacy, may not have identified enough studies for a meaningful review. Secondly, both informal and formal parenting support predict adequate parenting for parents with ID (McGaw & Newman, 2005) and thus understanding both these types of support is required to understand parents' experience of the support they receive. Finally, Thomas and Harden (2008) argue qualitative thematic syntheses should aim for a heterogeneous set of studies, rather than homogeneity which is the aim for statistical meta-analyses. Therefore, a review of both

formal and informal support filled a gap in the literature, adequately represents parents' experiences, and is in line with guidelines for qualitative systematic reviews.

As discussed, using the CASP (2018) checklist to draw conclusions about the quality of mixed methods designs, and papers reporting the experience of two different groups, has limitations (Heyvaert et al., 2013). However, it was felt that using a quality assessment tool was necessary in order to give the reader a flavour of the quality of the included studies. It is a strength of the review that no papers were excluded based on their scores as this would suggest inflated accuracy of the quality assessment measure. The use of a sensitivity analysis, and resulting removal of a theme, was also a strength of the review as it increased rigour.

There is some debate around the appropriateness of synthesising qualitative data. It has been argued that synthesising qualitative research de-contextualises the individual studies and that concepts identified in one setting are not applicable to others (Britten et al., 2002). Qualitative studies often include small sample sizes, and the aim is rarely generalisability. In order to preserve the context, details of type of support, setting and sample are provided in the review. This allows readers to judge the relevance of the studies included in the review (Thomas & Harden, 2008).

The papers in the review span a 23-year period. In this time, good practice guidelines for supporting parents with ID have been published (Department of Health & Department for Education and Skills, 2007) and further updated (WTPN, 2016) and the focus of research has

changed (Llewellyn et al., 2008). However, it was not clear from the current review if parents were experiencing support more positively over this time. The analysis did not focus on comparing experiences across time, which could be considered a weakness of the review. However, the range of participants' ages in some papers (for example, Theodore et al., 2018) suggest some parents are reporting from experiences over 20 years ago, making it difficult to identify trends in practice over time.

Future research

The majority of studies failed to explicitly adhere to Booth and Booth's (1994) recommendations for interviews with people with ID. Further research exploring the lived experiences of parents with ID should strive to follow these guidelines for higher quality data collection and to ensure respect for research participants. Similarly, in order to ensure higher quality research, future studies should strive to report researchers' values and assumptions (Elliot et al., 1999) and clarify the data analysis process to allow readers to judge the analytic rigour.

Future research could also address some of the limitations in the sample of the papers reviewed. Very little is known about the experience of fathers with ID (Llewellyn & McConnell, 2010). The limited research that has been conducted suggests that fathers with ID rarely receive support for their parenting, and feel left out of the support which is often focused on mothers (Dugdale & Symonds, 2017). Future research should explore how fathers' competence can be promoted (Tucker & Johnson, 1989) in order to ensure fathers with ID are able to access parenting support that meets their specific needs (DoH, 2009).

As discussed, the current review did not capture changes, or similarities, in experiences over time and thus a future systematic review could address this gap in the research. This would allow an understanding of whether policy change is contributing to a change in the lived experiences of parents with ID, or whether there is a policy-implementation gap in UK learning disability services (Rosli & Rossi, 2014).

Conclusion

In conclusion, this review extends the third phase of the evidence base (Llewellyn et al., 2008) and reports on the experiences of parents with ID. The results indicate support for parents with ID can both promote and inhibit their competence. People who support parents with ID should strive to promote parenting competence in order to increase the likelihood of competent parenting. This can be achieved by altering the narrative around parents with ID's ability to parent (Baum, 2007), and by following standard practices for working with people with ID to ensure support is accessible and meets the needs of this often marginalised client group (WTPN, 2016; McGaw & Newman, 2005).

Paper 2: Professionals' perceptions of the process of change during an attachment based parenting intervention (Video Interaction Guidance) with parents with intellectual disabilities

Abstract

Background and objectives: Parents with intellectual disabilities (ID) face multiple challenges to their parenting and an assumption of parenting incompetence. However, many parents benefit from evidence-based training programmes and with the right support are able to raise children effectively. In the UK, attachment-based interventions such as Video Interaction Guidance (VIG), are increasingly being used to support positive parenting and have been found to increase parenting sensitivity and attachment security. Despite VIG being offered to parents with ID, little is known about how VIG facilitates change for parents with ID specifically. The current study explored VIG guiders experiences of using VIG with parents with ID, and highlighted their perspectives on the outcomes of VIG, and the factors which facilitated and hindered change.

Method: Nine VIG guiders were interviewed about their experiences using VIG with parents with ID, guided by a semi-structured interview schedule. The interviews were transcribed and analysed using grounded theory, to develop a model of the processes of change.

Results: When VIG is conducted with parents with ID, VIG guiders report a positive impact on child development, parenting skills, the parent-child relationship, and the parent's relationship with the wider system. Importantly for parents with ID, these outcomes were facilitated by the visual aspect of VIG, the emotional response it elicits, and sharing successes with others, in the context of an attuned therapeutic relationship. In addition, VIG promotes the development of a new strengths based narrative, which contrasts to the disabling narratives held in society about parents with ID. The outcomes are further

facilitated by adaptations for parents' learning and psychological needs, and supervision for guiders, allowing them to reflect upon their assumptions about this client group. There are also interpersonal, intrapersonal and contextual factors which hinder the intervention.

Conclusion: VIG is a useful intervention with parents with ID. Although there are factors which may hinder its success for parents with ID specifically, appropriate adaptations can be used to compensate and promote positive parenting.

Keywords: parenting, learning disabilities, intellectual disabilities, video interaction guidance, attachment

Introduction

Parents with intellectual disabilities

People with intellectual disabilities (ID) have impairments in intellectual and adaptive functioning, with a developmental onset (Department for Health; DoH, 2001). While evidence suggests children born to parents with ID are in comparable physical health to children whose parents do not have an ID (Schuengel, Kef, Hodes & Meppelder, 2017), Emerson and Brigham (2014) found children who have parents with an ID are at greater risk of developmental delay, speech and language problems, behaviour problems, and frequent accidents and injuries. Parenting problems are significantly higher for parents with ID than those without, and thus parenting difficulties may elevate these risks (Emerson & Brigham, 2014). Increasing numbers of people with ID are becoming parents (May & Simpson, 2003), and thus the need for evidence-based parenting interventions for this client group is indicated.

However, in addition to cognitive impairments, parents with ID face multiple contextual challenges such as poor housing, single parenthood, social isolation, mental health difficulties and histories of abuse (Schuengel et al., 2017). These environmental factors are known to impact upon parent-child relationships (Llewellyn & Hindmarsh, 2015) and the development of a secure attachment (Belsky & Fearon et al., 2002). It can be theorised that parents who are exposed to contextual stressors may be less able to attune to their children's need (Meins, 2013) or mentalize their internal worlds (Fonagy, Steele, Steele, Moran & Higgitt, 1991), precursors to secure attachments, as their cognitive resources are directed at the contextual difficulties they face. Maternal mental health and experiences of

child abuse, more common in the ID population, are known to be a precursor to insecure attachment (Greig & Howe, 2001), as they can impact on parental internal working models, and thus the working models of their children. In addition, insecure or unsafe housing may make it more difficult for parents to create a safe base for their children, as they themselves do not feel safe (Maslow, 1943). In these ways, contextual challenges that parents face, which can occur more commonly in an ID population, may impact on the development of a secure attachment.

Therefore, although parents with ID often face a presumption of parenting incompetence (Gould & Dodd, 2014; Theodore et al., 2018), the relationship between parental cognitive impairment and child development may be mediated by these contextual factors (Llewellyn & Hindmarsh, 2015), and the impact these factors have on the development of a secure attachment, rather than being causally related to cognitive ability (Hodes, Meppelder, Moor, Kef & Schuengel, 2018; IASSID SIRG, 2008). When low socio-economic status is controlled for, the adverse outcomes for children are reduced (Emerson & Brigham, 2014). Despite this, parenting difficulties are often attributed to intellectual abilities, increasing the risk of children being taken into care (Booth, Booth & McConnell, 2004).

Interventions for parents with ID

Research is increasingly focusing on the abilities and support needs of parents with ID (Llewellyn, Mayes & McConnell, 2008). This is reflected in policy, with recent guidelines promoting the provision of personalised interventions for parents with ID (Working Together with Parents Network; WTPN, 2016).

Reviews of the literature (Coren, Thomaes, & Hutchfield, 2011; Wade, Llewellyn & Matthews, 2008) support the use of home-based behavioural training programmes to facilitate parenting skills. These interventions improved the mother-child interaction, child health outcomes and home safety, and improvements were maintained over time. Support for parents with ID also reduces the likelihood of maltreatment (James, 2004). However, studies rarely assessed whether parenting skills were generalised or considered the impact of context on parenting. The evidence base is marred by methodological limitations such as small sample sizes and limited use of blinding. Despite these limitations, it is generally acknowledged that parents with ID can and do benefit from parenting interventions which are tailored to parents' individual needs (McGaw & Newman, 2005).

A further limitation of the evidence base reviewed is the focus on practical parenting skills and behavioural training, rather than interventions with a relational or attachment focus. Given that the environmental factors that parents with ID are exposed to may impact upon parent-child relationships (Llewellyn, & Hindmarsh, 2015), and that people with ID are more likely to have been exposed to adverse childhood experiences which have the potential to disrupt the development of their own attachments (Vervoort-Schel et al., 2018), interventions with a relational focus are likely to be beneficial. Further research is needed to identify the parenting interventions which provide the right support to allow parents with ID to raise their children effectively (Tarleton, Ward & Howarth, 2006).

Video Interaction Guidance

Attachment theory states sensitive and attuned parenting promotes a secure attachment

and provides the child with a secure base from which to explore the world (Bretherton, 1992). Kennedy, Landor and Todd (2010) argue that in order to promote secure attachments, parenting interventions should focus on the relationship between the parent and child, rather than the behaviour of either the parent or the child. This allows for the development of 'attunement', defined as the responsive communication between parent and infant where emotions are shared in a reciprocal pattern.

Video Interaction Guidance (VIG), an attachment based parenting intervention, not developed specifically for parents with ID, focusses on the parent-child relationship. The VIG practitioner, known as a 'VIG guider', co-constructs a goal with parents around their parenting (Kennedy et al., 2017), for example "notice what he is trying to tell me" (Hunter et al., in prep). The guider then films the parent interacting with their child in contexts relating to their goal. In sessions known as the 'shared review', the parent is encouraged to reflect on their attuned interactions with their child and the VIG guider' supports the parent to make changes that will enhance their sensitivity to their child (Kennedy et al., 2010). VIG is conducted in cycles, with one cycle consisting of a filmed session and a shared review. While the number of cycles offered is flexible, with VIG guiders adapting the number of cycles needed to help parents achieve their goals, three to four cycles often produce significant change (Kennedy, 2017). The VIG guider also models sensitivity and attunement in the therapeutic relationship, which distinguishes VIG from other video-feedback approaches (Kennedy et al., 2010).

Video-feedback interventions produce statistically significant improvements in child development, parenting sensitivity and confidence, and reduce parenting stress (Fukkink, 2008). When compared to interventions focusing on parental representations of attachment or social support, parenting interventions which used video and focused on sensitive parenting increased parenting sensitivity (Bakermans-Kranenburg, van Ijzendoorn & Juffer, 2003).

In comparison to controls, mothers who received VIG were rated as being more sensitive in their interactions with their child (Kennedy et al., 2010), which is associated with attachment security (Bakermans-Kranenburg et al., 2003). VIG has also been found to reduce postnatal depression (Rackett, & Macdonald, 2014) and improve parental understanding of autism (Gibson, 2014). Additionally, parents who receive VIG are generally happy with their experience of the intervention (Doria, Kennedy, Strathie, & Strathie, 2014), value the opportunity to reflect, and find it empowering (Taylor, 2016). However, parents also felt judged for their parenting skills, and as such Taylor (2016) suggests further research is needed to explore the impact of VIG guiders upon the intervention.

Although there are some methodological limitations in the evidence base, such as non-randomised samples and a lack of triangulation of variables such as 'parental sensitivity', VIG is identified as promoting social and emotional well-being in the early years (National Institute for Health and Care Excellence; NICE, 2012).

Theoretical underpinning of VIG

Theoretical understandings of VIG are grounded in intersubjectivity theory (Trevarthen, 1998) which states infants have an innate capacity to initiate and respond to social cues. Parents and infants responding to each other's initiatives in a sensitive manner allows the development of moments of attunement, where infant and parent share subjective states while holding the other in mind. Trevarthen (1998) regarded this pattern of communication as the basis of all effective interactions.

Vygotsky's (1987) concept of a 'zone of proximal development' suggests children learn through interacting with a more experienced person who 'scaffolds' their learning, and helps them to develop new skills which would be beyond their reach without support (Kennedy, Ball & Barlow, 2017). During VIG, the parent is encouraged to reflect on the importance of being within their child's zone of proximal development in order to avoid overwhelming them with complex tasks. In turn, the VIG guider scaffolds the parent's learning. In this way, VIG aims to help families move towards attuned patterns of interaction, promoting sensitive parenting and secure attachments. Attuned interactions with caregivers are key for social, emotional, behavioural and cognitive development (Kennedy et al., 2017).

Explaining the success of VIG

Despite VIG's wide application and growing evidence for its utility, there is little empirical exploration of the processes by which it facilitates change. In order to address this, Doria et al. (2014) explored the perspectives of families who received VIG, VIG guiders and VIG

supervisors to generate an explanatory model of VIG's success. The authors analysed therapeutic sessions and conducted interviews and focus groups. The results indicated VIG improved family happiness, parental self-esteem and self-efficacy and changed attitudes and behaviours. The authors identified methodological components and underlying mechanisms that contributed to these outcomes.

Elements of the VIG methodology contribute to change (Doria et al. 2014), such as the VIG guiders' attuned responses to the parents' initiatives. The first videoed interaction generates a positive moment for the family, often a new experience for them. Additionally, guiders focusing on the family's successes, rather than their problems, increases self-efficacy. Notably, the authors found that positive and negative content generated about self and others was an important processes of change, highlighting that although VIG has a strengths focus, negative talk also facilitates change. Finally, the participants reported that video clips provided evidence of success, and this contributed to the outcomes of VIG.

Doria et al. (2014) also identified two underlying mechanisms of change. Firstly, metacognitive processes occur. Viewing video clips which highlight positive exceptions encourage families to reflect on their day-to-day parenting. To understand this, they consider their own and their child's thoughts and feelings during the interaction. Secondly, the family and VIG guider share in the construction of a new reality through continued reflection and discussion.

A strength of the study is the analysis of therapeutic sessions and interviews with both parents, guiders and supervisors, providing credibility checks on the model and ensuring quality in the analysis (Mays & Pope, 2000). However, although Doria et al. (2014) acknowledge that the limitations of VIG are under studied, they fail to adequately highlight factors which hinder VIG's success, or account for individual differences in outcomes. Further, the VIG supervisors in the study developed a model based on their shared understanding of factors identified by parents and VIG guiders. This approach may have meant the perspectives of individual VIG guiders and parents were lost. This may have been detrimental to the quality of the analysis, as the views of one group, in this case VIG supervisors, are over represented (Mays & Pope, 2000).

VIG as an intervention for parents with ID

Whilst there is no known published data on use of VIG with parents with ID across the UK, anecdotally, video feedback interventions are increasingly being offered to parents with ID; for example, it is known that a service specialising in support for parents with ID in the South West of England uses VIG as its primary intervention, and other generic children's services across London and the South East anecdotally report having used VIG with families where one or more parent is known to have ID. Interventions focusing on skill development, using a strengths-based approach, and taking place in service users' homes, are known to be beneficial for parents with ID (McGaw & Newman, 2005). Further, parents with ID value interventions which include videoing and reflection, and benefit from interventions which involve both parent and child (Ward & Tarleton, 2007). Video feedback interventions meet these criteria and are likely to benefit this client group.

Exploring this assertion using a RCT, Hodes, Meppelder, Moor, Kef and Schuengel (2017) found Video-feedback Intervention to promote Positive Parenting (VIPP), an intervention with broad similarities to VIG, significantly reduced parenting stress for parents with ID. However, while the authors hypothesise that VIPP may alleviate parenting stress by reducing social isolation or equipping parents with the knowledge and skills to interact with their children, and that the quality of the therapeutic alliance may impact upon outcomes, they fail to explore these hypotheses empirically. As such, the authors suggest future research should explore the processes through which video interventions achieve change with parents with ID.

In addition to reducing parenting stress, video feedback interventions also meet the goals identified by parents with ID. Using goal-based outcome measures, Hunter, Murphy, Black and Hockaday (in preparation.), found VIG helped parents to achieve their goals related to communication and the development of the child-parent relationship. Exploring the factors that facilitated change, a qualitative element revealed the parents identified improved parenting confidence, improved understanding about attachment, and the relationship with the guider as important parts of the intervention. However, the qualitative interviews were brief and some parents struggled to reflect upon the intervention. This may have meant there were themes, such as factors which mediate or hinder change, which did not emerge. Further, the majority of the parents were undergoing child protection proceedings, and, due to concerns about children being removed from their care, may have given positively biased accounts of their goal achievement.

In addition to improving understanding about attachment (Hunter et al., in prep.), VIG has the potential to impact upon the attachment behaviours of parents with ID. A case study found a mother with mild ID who received VIG increased the frequency of her sensitive interactions with her child and engagement with support services, suggesting the intervention promoted secure attachment and reflective parenting (Pethica & Bigham, 2018). However, this mother found it difficult to generalise her learning, and therefore VIG may be limited as a stand-alone intervention with this client group. Although this study demonstrates the feasibility of VIG, the single participant clearly limits generalisability.

The present study

The literature suggests that video feedback interventions such as VIG benefit parents with ID (Hodes et al., 2017; Hunter et al., in prep; Pethica & Bigham, 2018). While there have been attempts to explore the factors which contribute to success in a sample of parents without ID (Doria et al., 2014) these have not been adequately explored in a sample of parents with ID. Although it is arguable that Doria et al.'s (2014) findings could be generalised to parents with ID, this would ignore that interventions for this client group make adaptations for their learning capacities and deficits, their ability to generalise their learning, the consequences of poorer memory and attention, and executive function difficulties (Hodes, Meppelder, Schuengel & Kef, 2014).

Further, the high rates of attachment trauma in the ID population (Granqvist et al., 2014; Vervoort-Schel et al., 2018), and the contextual factors parents with ID face which impact upon parent-child relationships (Llewellyn & Hindmarsh, 2015), are likely to affect the

process during attachment-based interventions. Therefore, research exploring the processes of change during VIG for parents with ID specifically is indicated. It is anticipated that a VIG guider who has a better understanding of the factors which facilitate or hinder VIG for parents with ID specifically will be able to tailor the intervention to best meet the needs of this client group.

Parents with ID's perspective on the process of change during VIG has been explored (Hunter et al., in prep.), although the small sample size and brief interviews limit the conclusions which can be drawn. Doria et al. (2014) found that the perspectives of VIG guiders provided novel data, and furthered the understanding gained from parents' perspectives. Therefore, further research understanding factors that facilitate change, from the perspective of VIG guiders working with parents with ID, is likely to extend the current knowledge.

As such, the present study explored the perspectives of VIG guiders to answer two research questions, and identify implications both clinically and theoretically, in order promote the effective application of VIG with parents with ID. It was anticipated that there would be both similarities to and differences from previous research. The present study will focus specifically on VIG, as the prominent video interaction intervention used in the UK.

- 1.** What is the impact of VIG when working with parents with ID, from the perspective of VIG guiders?

2. What are the factors that facilitate or hinder VIG with parents with ID, from the perspective of VIG guiders?

These research questions will be addressed using a constructivist grounded theory approach, which is appropriate when there is a paucity of research in the area of interest (Charmaz, 2006). Further, grounded theory is often used when exploring process issues, and thus is a suitable method for addressing the research questions of the current study (Charmaz, 2006). Grounded theory was also selected as it subscribes to a similar epistemology to VIG (Kennedy et al., 2017) and is considered a stringent method of data analysis, where results remain grounded in the data (Glaser & Strauss, 1967).

Method

Ethical approval

Ethical approval was granted by both the Health Research Authority (Appendix 3) and Royal Holloway University of London Research Ethics Committees (Appendix 4). Participants were recruited from five health and social care services across England and Wales which provide VIG. At each site, permission to conduct research was gained from the Research and Development department.

In order to ensure respect for participants (Elliot, Fischer, & Rennie, 1999) all participants gave informed consent and were reminded of their right to withdraw. No risk issues were raised during the research process.

Design

Choice of methodology.

A qualitative approach was selected to enable in-depth analysis of participants' experiences of delivering VIG with parents with ID, in order to answer the research questions.

Qualitative research is often indicated as an appropriate methodology where there is a paucity of research in the area (Turpin, Barley, & Scaife, 1997), as there is little theoretical grounding for questionnaire methods. In addition, qualitative methods allow for an exploration of processes of change (Burck, 2005) and contextual issues (Yardley, 2000).

The study used a semi-structured interview design which encouraged participants to expand upon their answers. Semi-structured interviews are appropriate for research exploring

process issues (Smith, Harré, & Van Langenhove, 1995) and thus are indicated as an appropriate methodology for the current study.

Charmaz's (2006) constructivist grounded theory was chosen as the method of analysis. Grounded theory is an inductive discovery approach that allows for the development of a theoretical account which is grounded in the data (Glaser & Strauss, 1967), and is appropriate when there is limited knowledge of the area of interest (Charmaz, 2006). The study aimed to explore the process of applying VIG with parents with ID to promote the sensitive and effective application of VIG with this client group. Therefore, this goal is facilitated by developing a theoretical model, grounded in data, which has more explanatory power than the identification of themes in unstructured data, as is the case in thematic analysis (Birks & Mills, 2015). Additionally, grounded theory remains close to the data, and uses less interpretation than Interpretative Phenomenological Analysis (Sandelowski, 2010).

Charmaz (1996) argues grounded theory can be used by researchers who subscribe to a range of epistemological assumptions. Charmaz's (2006) constructivist approach was adopted as it allows the researcher to account for, and reflect upon, their prior knowledge and assumptions which can impact upon the data. In addition, VIG takes a social constructionist approach as the client's reality is co-constructed with the therapist throughout the intervention (Kennedy et al., 2017). Therefore, a constructivist method of analysis is in line with the epistemology of VIG.

Materials.

The semi-structured (Appendix 5) interview schedule was developed in line with the research aims, and findings from previous research in the area (for example, Doria et al., 2014). In order to assess the appropriateness of the interview schedule, a VIG guider who works with parents without ID reviewed the interview schedule and offered comments. The interview schedule was reviewed after each interview in order to further explore areas of interest.

Position of the researcher.

The researcher's perspectives cannot be separated from the qualitative research process (Elliot et al., 1999). In line with a constructivist approach, the researcher reflected on their own theoretical orientation, values and assumptions, using a reflective log (Appendix 6). This helped to 'bracket' these assumptions and thus reduce their impact on data collection and analysis (Willig, 2008).

Equally, transparency regarding the researcher's position is important to help the reader judge the potential impact on the research process. I, the lead researcher, am a female trainee Clinical Psychologist, with an interest in parenting and attachment theory. I do not have any children, or any close friends or relatives with children, and thus my experience of parenting is mainly from an academic and clinical perspective, as well as my own experience of being parented. During the time I conducted the interviews, I worked at an inner-city service for adults with learning disabilities. While this increased my interest in and understanding of some of the experiences and challenges discussed by participants, it may

also have impacted upon my objectivity. I developed a particular interest in social discourses around disability, and the impact of power on therapeutic interventions with people with ID. In addition, I have a female relative with a learning disability who is of child bearing age, which further increased my interest in the research. While I have not conducted VIG myself, I previously worked at a service which used the approach and thus had some practical understanding and knowledge of the literature related to VIG prior to beginning the research. This guided the development of the research questions and interview schedule.

Participants.

Grounded theory calls for a heterogeneous sample (Charmaz, 2006). Nine female participants were recruited from therapeutic services across England and Wales. The participants were VIG guiders who had worked with parents with different severities of ID, representative of the diversity of parents with learning needs accessing parenting support. The VIG guiders worked in both urban and rural settings, with different levels of experience and professional backgrounds. Demographic information is presented in Table 4 in order to situate the sample and allow the reader to judge the relevance of the study (Elliot et al., 1999).

The inclusion criteria for the study was VIG guiders who had conducted a VIG intervention with a minimum of one parent with ID in the last three years. However, the majority of participants reported having working with a parent with ID within the last year and all reported good recall of the intervention. To ensure fidelity to the VIG protocol, all VIG guiders were required to be accredited by AVIGuk.

In line with methods of identifying ID commonly utilised in research, the present study relied on proxy reports of ID from VIG guiders (Brooker et al., 2015). As not all VIG guiders who support parents with ID work in specialised ID services, some of the parents do not have a formally diagnosed ID. Although parents without formal diagnoses are likely to have milder intellectual impairments, they face similar issues to parents with diagnosed ID (Tarleton, 2015). Therefore, for the purposes of the study, 'parents with ID' were defined as either those with a formal diagnosis of ID (defined as significant impairment in intellectual and adaptive functioning, presenting from childhood with lasting impact into adulthood, American Psychiatric Association; APA, 2013) or those with a 'working diagnosis' of ID, which required reasonable adjustments to support provided by the clinician.

Table 4

Participant demographic data

Participant	Age	Gender	Ethnicity	Profession	Year VIG training began	Level of VIG training	Service	Experience of using VIG with parents with ID	Medium of interview
1	45	Female	White British	Specialist intervention worker	2013	Advanced practitioner and supervisor	Family and parent support service with an ID pathway	Two parents with diagnosed ID and four parents with a working diagnosis	Skype
2	47	Female	White mixed	Early childhood educator	2015	Advanced practitioner and trainee supervisor	Perinatal mental health service	One parent with diagnosed ID	Skype
3	38	Female	White African	Teacher and family support worker	2016	Accredited practitioner	Children centres	Two parents with diagnosed ID	Face to face
4	30	Female	Mixed white	Clinical psychologist	2015	Accredited practitioner	Service for adults with ID	One parent with diagnosed ID	Skype

5	49	Female	White other	Teacher and contact supervisor	2012	Advanced practitioner and supervisor	Children centres	Three parents with diagnosed ID	Face to face
6	45	Female	White British	Social worker	2012	Accredited practitioner	Children centres	One parent with diagnosed ID	Face to face
7	49	Female	White British	Clinical psychologist	2011	Advanced practitioner and trainee supervisor	Service for parents with ID	Twenty-five parents with diagnosed ID	Skype (audio only)
8	43	Female	White British	Clinical Psychologist	2017	Trainee practitioner	Service for parents with ID	Five parents with diagnosed ID	Skype (audio only)
9	24	Female	White British	Assistant psychologist	2016	Trainee practitioner	Service for parents with ID	Eight parents with diagnosed ID	Skype (audio only)

Sampling.

A snowball sampling approach was used. The researcher contacted services known to use VIG with parents with ID, which facilitated communication with other services. This sampling method has been used to identify supporters of people with ID (Donovan, 2002). In addition, the researcher contacted sites which had published research about the use of VIG with parents with ID. Participants were recruited from a total of five sites. Two sites identified as having used VIG with parents with ID did not return contact.

Procedure

All participants were initially approached by the lead researcher, or by their manager who had been approached by the researcher, to find out if they were interested in taking part in the research. Those who were interested in participating were sent a participant information sheet (Appendix 7), and given at least 48 hours to review this and consider if they would like to participate in the research. The researcher arranged a time to discuss the information sheet with the participants, and answer questions about the study's aims and methodology. A time for the interview was arranged and all participants gave written consent to participate (Appendix 8).

Semi-structured interviews were conducted either face-to-face or over Skype. Due to technical difficulties, some interviews used only the audio capabilities of Skype. The participant completed a demographics questionnaire (Appendix 9). The participants were then asked about their experiences of delivering VIG to parents with ID, guided by the interview schedule (Appendix 5). The participants were debriefed and thanked for their time and all participants agreed to be contacted to review the theoretical model.

A draft of the model was sent to all participants in order to provide credibility checks (Cooney, 2011) and five participants offered feedback (Appendix 10). This feedback was incorporated into the final model.

Data analysis

Transcribing.

The interviews were transcribed verbatim by the researcher, allowing the researcher to become immersed in the data (Charmaz, 2006). The interviews were deleted after transcribing was completed.

Coding.

Each transcribed interview was analysed using the steps outlined by the grounded theory methodology (Charmaz, 2006). During initial coding, each line of the data was named to summarise its meaning, often using the same language as participants used (Appendix 11). This reduced the opportunity for the researcher to impart existing assumptions and ideas on to the data, ensuring the theoretical model remains grounded in the data (Charmaz, 1996). The research supervisor reviewed initial coding to ensure fidelity to the grounded theory methodology.

To ensure quality in the qualitative analysis, a second reviewer provided credibility checks for the initial coding (Elliot et al., 1999). The second reviewer conducted line by line coding on a third of the interviews ($n = 3$), which were selected using a random number generator. The lead researcher and second reviewer reflected on similarities and differences in their codes. They found a good level of agreement, suggesting that the lead researcher's codes

were appropriately and sufficiently grounded in the data. An absolute level of agreement was not calculated as, in line with the constructivist epistemology, it is acknowledged each researcher has a different construction of the data (Charmaz, 2006). Instead, the discussion encouraged the researcher to reflect on the data analysis process and highlighted times initial codes had strayed from the data. Based on this reflection, the lead research revised their initial codes.

Next, the researcher conducted focused coding to begin to synthesise data (Appendix 12). The most significant or frequent codes were used to identify conceptual themes (Charmaz, 1996). The initial codes became categories, and an understanding began to develop of the conditions under which categories arose, were maintained, or changed (Charmaz, 1996). These were further developed into theoretical codes (Appendix 13). During these stages, the researcher was mindful to take an inductive approach to avoid making data fit with preconceived ideas (Charmaz, 2006), facilitated by the reflective log (Appendix 6).

Diagramming was used to develop a theoretical model to explain the data.

The final stage of the grounded theory analysis involved writing analytic memos about the data to record the researcher's understanding of the developing model (Appendix 14). The memos considered relationships between categories and the meaning of codes (Sbaraini, Carter, Evans, & Blinkhorn, 2011). The researcher reflected upon processes that emerged, the consequences of processes and the conditions under which they occurred.

Service user involvement

In addition to participant (VIG guider) involvement in reviewing credibility of the model

developed, support was also sought from a self-advocacy group for parents with ID to ensure the clinical recommendations of the research resonated with people with ID. In addition, the group reflected on the role of narratives in the experience of being a parent with an ID. The visuals used to help orientate parents to the VIG intervention and a summary of parents' feedback can be seen in Appendix 15. The feedback from the service user group was incorporated into recommendations for VIG guiders working with parents with ID.

Results

The results of the analysis, 11 theoretical codes and 36 focused codes, are presented below. These results represent the perspective of VIG guiders. Theoretical codes are underlined and focused codes are italicised. Extracts, in the form of quotations, are included to ground the results in the data (Elliot et al. 1999). Appendix 16 indicates the number of participants that contributed to each focused code.

Pre and early VIG

Parents and parenting before VIG.

Parents' view of parenting, self and child.

Before beginning the intervention, the participants felt that parents had a broadly negative view of parenting, themselves as a parent, and their child. The parents were described as viewing parenting as “*task orientated*” (participant 2), and some parents “*didn't think [their] children liked [them]*” (participant 8). The parents' experience of being different contributed to limited parenting confidence.

“One of the biggest things [for] parents with learning disabilities (LD) is their confidence. There is this perception of them being different, they have experienced difference all their lives, at school and with services.” (participant 1)

Parenting skills before VIG.

The participants suggest that sensitive and attuned parenting skills were limited before the intervention. The guiders noted the importance of beginning the intervention at the level of the parents' understanding.

“He literally just wasn’t sure if he was holding his baby ok. And if we think about that, such a fundamental basic [...] So I think it’s really starting at where they, what they are worried about.” (participant 1)

Negative expectations.

Some parents had negative expectations for their interaction with the guider, concerned that they would be criticised and “*shut down*” (participant 4). Other parents were described as having a negative expectation of their own ability to do VIG.

“Well the dad didn’t really want to engage with it, didn’t want to or didn’t feel able to... I think he just thought the whole thing was a waste of time.” (participant 6)

Concerns about filming.

The VIG guiders felt that the majority of parents had concerns about, and were resistant to, being filmed. Filming was experienced as “*intrusive*” (participant 9) and “*intimidating*” (participant 2), and parents were “*scared*” (participant 1) about what the film would be used for. Guiders hypothesised that parents’ previous experiences with services had involved scrutiny and criticism, feeding into their concerns. These concerns were “*one of the biggest barriers*” (participant 7) to engagement.

“It needed a lot of explanation around what the video was used for [...] she’d been under a lot of scrutiny from social services... she thought there was a hidden agenda [during VIG].”
(participant 4)

Guiders found it helpful to spend time ensuring parents understood the purpose of the video, and to reassure them that the intervention focused on strengths. Guiders used *“a lot of encouragement, patience, reassurance during the first filming.”* (participant 9).

“It’s about helping them understand that it’s only the very positive clips that we use.”
(participant 8)

Engagement.

Difficulties with engagement.

The guiders described barriers to engagement which hindered VIG. Parents were thought to use avoidance, either missing sessions or not engaging with the video in the sessions.

“He just sat there and kind of, I offered whether he wanted be in the room, did he want to see these clips, did he want me to explore this and he was like ‘I don’t care’.” (participant 6)

The guiders considered some of the reasons parents found it difficult to engage with VIG. For some parents, their own needs, either emotional or related to their ID, made it difficult to focus on the intervention.

“He wasn’t in the right place [to do VIG] and whether that is due to mental health or because of his LD, I’m not quite sure, but he couldn’t focus at all.” (participant 8)

Some guiders reflected how their own style may have hindered engagement. Some commented they went *“too quickly”* (participant 6), or that they were not perceived as open. Several guiders noted that austerity measures and cuts to services meant there was limited time or resources to engage the parents who found the intervention most daunting.

“I’ve shied away from doing it at times, and I didn’t push them [...] rather than the LD person themselves not wanting to do it. You might need longer, like to persuade the father with the tic, I would of loved to spend a long long time with him, but I went back and said ‘I don’t think it’s the right time to do VIG at the moment’. You know because there was a time pressure.” (participant 8)

Factors which improved engagement

However, all participants discussed factors which they felt promoted engagement, for example establishing a good and collaborative therapeutic relationship.

“Spend more time on the initial stages [...] making people feel secure. I would imagine lots of parents with LD have had difficult experiences and not had that stable relationship, so that might be newer to them.” (participant 9)

There were also elements of the VIG model itself which were identified as promoting engagement and allayed some of the parents' concerns. These were identified as the "*focus on the positives*" (participant 9), the experience of being filmed, and the first shared review.

"I mean there was [difficulties with engagement] initially but then I think once she'd experienced the filming and how just non-threatening it is and how non-threatening the review is, it's really ok." (participant 4)

During VIG

Process of change during VIG.

The analysis highlighted the participants' perspective of the processes of change which facilitated outcomes.

The visual aspect of VIG.

All participants suggested the visual aspect of VIG was an important process of change. Parents were able to see themselves "*being successful*" (participant 4). Parents also saw "*exceptions*" (participant 1); seeing themselves parent differently to their typical parenting. This, participants suggested, led some parents to reflect on this difference and thus adapt their parenting.

"There's certainly something incredibly powerful about seeing yourself or seeing how your child looks at you and being able to reflect on that and I think sort of start to alter a perception." (participant 1)

“I suppose by watching the video they start noticing things that they hadn’t noticed about themselves before [...] and maybe it doesn’t fit with what they do at other times, so then they do more of it.” (participant 7)

The visual aspect was considered particularly important for this client group as it overcame some of the challenges with language.

“It’s visual so it kind of bypasses maybe problems people might have with verbally understanding, particularly when you’re talking about quite complex and abstract concepts.” (participant 7)

The visual aspect of VIG was also thought to provide evidence of change. This is particularly important for parents with ID who often face evidence, for example from social care, highlighting their limitations.

“Having the evidence in front of them, that they are a positive person, that their child likes them and loves them.” (participant 8)

The emotional aspect of VIG.

Participants suggested that seeing successes and exceptions led parents to experience positive emotions. It can be hypothesised that this was reinforcing and led parents to repeat the behaviour.

“You can see people have a warm fuzzy feeling and they feel that emotional connection and they start to notice good stuff and they laugh and they feel really nice and they notice more good [...] there’s a mechanism that when you watch it, it makes you smile, and it makes parents want to do it more.” (participant 7)

Parents were also thought to experience negative emotions during the shared review, which also led them to change their behaviour, possibly because of a realisation that the positive clips deviated from their normal parenting.

“We’ve shown lovely clips and then when I’ve shown them they’ve cried and I think that’s almost where they’re realising how lovely it could be but they know that they’re not giving their child that at other times and there’s some sadness [...] I think that’s sort of the other side of cognitive dissonance, it can motivate people to make changes.” (participant 7)

Sharing success.

The positive reinforcement parents received from a variety of external sources was also identified as a process for change. Successes were shared with family members and at social care reviews.

“We did sticker charts, which don’t really exist in VIG. [...] We got her partner involved and he was giving her a star every time he noticed she was doing one of the attuned behaviours.” (participant 4)

“She had a desire to sort of share the positives [with social care] and VIG lends itself to that.”

(participant 6)

The therapeutic relationship in the process of change.

Guiders felt they were able to use the therapeutic relationship to “*model [...] accepting initiatives*” (participant 4), mentalizing and emotional attunement. This was often a new experience for parents.

“People might not have experienced someone related to them in a very attuned way before [...] will hopefully enable them to reflect on that and think about what they offer to their child. It’s not just about videos.” (participant 7)

The therapeutic relationship was thought to offer a different power balance compared to parents’ previous experiences with services. Parents’ ideas and initiatives were valued and celebrated, parents were given “*choice*” (participant 3), and differences of opinions were respected. Parents were encouraged to take an active role in the intervention, with guiders “*following [their] lead*” (participant 2). This was thought to empower parents, increase their confidence and agency, and contribute to behaviour change.

“I think VIG allowed a different therapeutic relationship to what she’s used to [...] I guess I put her very much in control of the VIG process and I took a step back.” (participant 4)

“So it was allowing a safe space to have differing points of view, [...] and importantly the confidence to bringing up their voice, the confidence to say what they’re thinking.”

(participant 9)

A new narrative.

Participants suggested that the way parents thought and spoke about themselves, their child, and their relationship began to change as their confidence increased.

Parents’ changing perception and understanding of themselves as a parent.

Guiders noticed parents began to recognise their own role in parenting and their impact on their child. Parents began to acknowledge their own successes, build a narrative of themselves as effective parents, and were described as feeling more confident in their parenting ability.

“The mum I think started to see herself as somebody who is a bit more competent.”

(participant 6)

Parents’ changing perception and understanding of their child.

Participants felt that parents began to have a different understanding of their child’s internal world and this contributed to a more positive perception of their child.

“Someone who has used ‘challenging difficult angry’ to describe their child and at the end its ‘kind helpful funny loving’ [...] their perception of the child has changed.” (participant 1)

Parents' changing perception and understanding of their relationship with their child

Parents began to view the relationship more positively and understand the importance of an attuned relationship for their child's development.

"I think they have more positive language of their relationship together." (participant 9)

The impact of a new narrative.

The parents' new strengths-based narrative was described by participants as contributing to behaviour change.

"I think that if you have a negative view of your child, you think their behaviour is going to be informed by that view, 'he's a naughty boy' and you're going to respond negatively, whereas if your view of your child is actually 'he's doing that when he needs my attention' then of course your behaviour is going to change." (participant 7)

Post VIG

Outcomes of VIG.

All of the guiders noted that the process of change described contributed to concrete changes in the lives of parents, their children, and within relationships, as the new narrative began to take root in their lives. It was felt a lot was achieved in a relatively short time frame and outcomes were *"comparable for someone with a significant LD as someone with a very high IQ"* (participant 1).

Impact on child development.

Participants noted VIG impacted on child development. Children's language increased and they made "more initiatives" (participant 4) for communication.

"The child he just, I can't even tell you, the increase in spoken language." (participant 3)

Impact on parent-child relationship.

Parents were reported to be more connected to their child and both parent and child found more enjoyment in the relationship. This was thought to positively impact upon attachment.

"Yeah so the first time I met him... he held the child. There was no interaction there was no playing there was none of it. And by the time I left they had a really like lovely relationship where there was lots of interaction lots of smiling and laughing." (participant 3)

"I think the impact can be [...] just being more connected with the baby, with their child." (participant 1)

Improvement of parenting skills.

Both the quantity and quality of parenting skills were described as improving. There was an "increase in attuned behaviours" (participant 4) and mentalizing. Parents' ability to reflect on their parenting also increased.

“So it felt a little bit like she was recognising her role in helping him learn, but also the way that she could use her imagination to help him behave [...] instead of shouting at him, ‘I can pretend something with him, and that will encourage him to walk down the street with me’.”
(participant 2)

“I can remember someone saying ‘yeah it’s like he understands me now and I understand him’ you know, that’s mentalization and that’s what she had felt had changed.” (participant 7)

Impact on parents’ relationships with the wider system.

Participants described how parents’ relationships with services changed after VIG. Some parents had increased insight into their support needs, and engaged with services as a result, for example asking for a *“parenting course”* (participant 4).

“He could also see where potentially his learning need was [...] he could say what he was good at and where he needed more help.” (participant 3)

However, participants also spoke about limitations to the outcomes that were achieved during VIG.

“By [the end of VIG] the child was separated and in a foster placement [...] I was a bit disappointed if I’m honest about how little progress there was.” (participant 6)

Limitations to outcome measures.

The participants described difficulties with the VIG outcome measures with parents with ID.

“So we do a lot of outcome measures [...] it’s not very accessible. We ask them three words to describe you, your child, any three words. And then any three words to describe you as parent then any three words to describe your relationship with the child. And sometimes I think they sort of slightly struggle with that.” (participant 1)

“I mean the transformation was so immense, I don’t think that was captured as well as it could have.” (participant 3)

Some guiders “*adapted paper work*” (participant 3) to make it more accessible while others avoiding using paper work, instead using storytelling and the video to explore change.

“Letting her like do some story telling in terms of how she’s feeling, like the process of it was probably more helpful than her actual answers.” (participant 2)

“At the end what’s more effective as an outcome measure is simply counting the amount of attuned interactions in the last video.” (participant 4)

The impact of ID on VIG

The parents’ ID makes the intervention difficult.

All participants spoke about ways in which they considered parents' ID to impact upon the intervention, often making it more difficult.

Difficulties with expressive and receptive language.

Parents were often described as finding it difficult to express their emotions, abstract concepts and to describe change. Speech was limited, with some parents only providing "yes or no" (participant 6) answers. Some parents also struggled with their understanding of language.

"I think with VIG some of the language like 'initiatives'... the parents that I work with didn't understand." (participant 1)

Participants described how parents' difficulties with language can draw their focus away from the video, limiting their engagement with it.

"I think especially with people with LD who are really worried about their children, they're really keen to make sure they say the right thing, and unfortunately that paired with a very enthusiastic guider can mean actually parents focus on saying the right things, rather than focusing on what they're trying to watch." (participant 9)

Difficulties with memory.

Participants suggested that parents' memory difficulties made it hard for them to hold their learning in mind between sessions, limiting the change that was achieved.

“For all of them it was difficult for them to remember [...] what we did last time, what we discussed [...] I’m not sure whether they can kind of retain and remember this up until next time.” (participant 5)

Difficulties with abstract thought.

Although the video helped to make the intervention concrete, the protocol also encourages reflection on abstract concepts. Participants suggested that parents found this difficult and often struggled to develop an understanding beyond what they saw in the video.

“That made the steps to go beyond development of new ideas very difficult because um this mum in particular did not have the capacity to express the abstract thought that was necessary to have those kind of metacognitive conversations. [...] I think we got change but we didn’t get change through the metacognitive stuff.” (participant 4)

Difficulties with generalising learning.

Parents were thought to find it difficult to generalise their learning beyond the shared review and to different types of interaction. Some participants felt parents didn’t understand the need to generalise, and others felt generalisation difficulties were due to comorbid mental health needs.

“Although we saw [attunement] it didn’t generalise to different forms of play. We did free play as a basis for filming and then on the last session we tried some structured play and um she went into a very controlling interaction with her kid.” (participant 4)

“Some of the parents that haven’t generalised, it isn’t due to their learning, it’s to do with [...] comorbid mental health difficulties which has meant that their child hasn’t sort of been at the forefront of their attention.” (participant 7)

Parents’ overestimation of their parenting abilities.

Guiders felt that the positive focus of VIG, combined with parents’ limited insight into their difficulties, meant some parents overestimated their parenting skills. Some disengaged from the intervention, feeling they were parenting effectively, when the guider still had concerns around their parenting.

“I’m conscious that there is a danger that those parents could of gone away thinking that everything was great [...] because you’re focusing on that stuff” (participant 6)

Adapting the VIG protocol to increase accessibility.

Despite parents’ ID impacting upon the process of VIG, all participants highlighted ways in which VIG could be adapted to parents’ needs to facilitate the intervention’s success.

Using concrete learning tasks, pictures and repetition.

In a response to parents’ difficulties with memory and the abstract concepts in VIG, participants encouraged parents to write or draw their learning which helped them to understand and retain information. Participants also encouraged parents to repeatedly review stills and video clips *“again and again and again” (participant 5).*

“We paused the film and let her write down some thoughts that she was having and draw some pictures [...] that seemed to really help her kind of retain the information, using that really concrete method.” (participant 2)

“I would take a picture of the video that I was showing her and put little thought bubbles next to it. I used that to help us do ‘what do you think he’s thinking’ or ‘what do you think he’s feeling’ or ‘what are you thinking now about this’ [...] trying to get that as concrete as possible.” (participant 4)

“I would get the parent to re-watch the video clips of the best interaction daily because [...] a parent without LD I would imagine they could hold that picture of that successful interaction in their mind and mull it through, but parents with LD actually being able to re-watch themselves being successful, really really helpful.” (participant 4)

However, some parents were described as finding this patronising and the use of pictures undermined the empowering stance of VIG.

“She finds it a little bit patronising when I use the pictures and she sees it as ‘I’m not stupid, why are you showing me these children’s pictures’ [...] it’s like I’m saying ‘well you’re not good enough to understand me verbally so you need to be looking at this picture’.”
(participant 5)

Going slowly and having more sessions.

To compensate for parents' slower processing speed, participants "[went] a bit slower, [and did] more sessions" (participant 7).

"It might take a few more sessions maybe so taking it at a slightly slower pace and really making sure you've got those foundations of shared listening, shared space." (participant 9)

Using simple language.

Guiders adapted the language they used, using simpler language or the parent's language.

"The language [is difficult] so I would just keep things really simple and just use much more language that they would be able to access and understand and very much using their language within the shared reviews." (participant 1)

Modelling parenting skills.

Participants modelled parenting skills, in an attempt to compensate for parents who did not have a good model of being parented themselves. This helped parents to interact with their children more positively on film, increasing the number of positive interactions which could be reflected on in the shared review.

"An adaptation I did for the parent with LD was some modelling sessions as well [...] I would do like phases of VIG followed by phases of parenting, as in teaching parenting, modelling parenting, modelling some directive play and then allow her to do it just so it can be

successful. Because otherwise this is a person who has LD who's been raised in foster care who's been removed when she was a toddler. She had no clue what appropriate play was."
(participant 4)

Managing overestimation of parenting skills.

Participants considered how to manage parents' limited insights into their parenting needs, and perceived overestimation of skill. Guiders encouraged parents to consider how the positive parenting on screen differs to their everyday parenting. Guiders felt they needed to make explicit that parents were seeing a successful moment, and to help parents understand what is needed for change to be maintained.

"Well what I would be doing is weaving [the negatives] in [...] you're not thinking about all the bits that are going wrong, but you might start saying things like 'oh and so how is what we're seeing here different from other times' that might be one way in, and then you're bringing in difference of opinion [...] there has to be some gentle challenges, it's not just about reinforcing the good." (participant 7)

Promoting generalisation.

Participants found it facilitated the intervention when they used *"formulation"* (participant 7) to understand generalisation difficulties, and filmed across different settings. In addition, participants used a directive approach to encourage parents to generalise.

“I felt she would have benefited from a kind of more [...] long-term approach where you do a bit of work around free play, you do a bit of work around structured play, you do a bit of work around meal times. Always using VIG but umm focusing on different things to aid the generalisation because obviously that’s a difficulty for people with LD.” (participant 4)

“I’m more directive [...] so I may say ‘and remember from today, next time when you come to contact, smile’.” (participant 5)

Contextual factors impacting VIG

Societal narrative of ID.

Negative and stigmatised views of parents with ID.

Participants discussed the stigmatising narratives held in society about people with ID.

“As a society, we think subconsciously that parents with additional needs can’t be good parents.” (participant 3)

This narrative may have meant that parents did not feel confident making initiatives during the shared review. They often felt powerless, resigned to their lack of control, taking a *“passive approach” (participant 1).*

“It’s being aware I think for the parent with LD that their initiatives have basically received so much negative feedback throughout their lives that they do very very very few. And it’s important to pick them up when they do and give them space, [...] these people haven’t

really been responded to all their life so why would they make an initiative if their expectation is that you would just shut them down.” (participant 4)

Impact of social services on VIG.

All of the guiders reported that the parents they had worked with had some involvement with social care. This was thought to both facilitate and hinder VIG.

Social care had a positive impact on VIG.

Many parents were referred into VIG by a social worker, and for some this helped engagement.

“I was reflecting on it today, would they have put in as much effort if social services weren’t involved? [...] It really worked in their favour.” (participant 3)

In addition, the involvement of social care meant the guiders felt they were able to focus on building a therapeutic relationship, knowing that risk was being held by the social worker.

“In a way it was helpful to have social services there because it meant I could focus on the VIG intervention. There were times when I went to her house and I thought ‘hmm’ but then I know there’s someone seeing her for that reason, I know there’s people there who are monitoring that so I’m not taking on any of this.” (participant 4)

Social care had a negative impact on VIG.

Despite the potential for social care to support VIG, parents' mistrust of social care was often inferred as translating into a mistrust of the VIG guider. The focus of social care on parenting limitations and challenges was at odds with the strengths-focused approach of VIG.

"Because she was going through a child protection procedure and feeling very criticised, and so she was sort of believing what people were saying [...] and that was creating a sense for her that she wasn't a very good mum [...] I can really see how positive things you're doing may get really lost." (participant 9)

Parents felt judged by social care and were *"terrified every day"* (participant 1). For some parents, their concerns about revealing parenting vulnerabilities was described by participants as leading them to *"mask their difficulties"* (participant 9) from the guider. This made it difficult for the guider to gain a true understanding of the parent and their needs.

"She was involved in child protection, and I think because of that, she only really used positive language. Because I think she needed to project 'I'm doing a good job and everything is ok'. So yeah so even when we started [...] it was things like 'we're happy, I'm happy, he's happy'." (participant 2)

Individual differences impacting VIG

Parental individual differences.

Parents' own psychological needs.

The participants described the process of VIG as being hindered by parents' own experiences of being parented and their associated attachment needs, as well as parental anxiety and depression.

"The trauma actually preventing them from being more attuned and more sensitive to their children." (participant 5)

"Mental health issues and anxiety that seemed to make it harder in terms of the initial engagement and then the shared review would become less about the VIG and more about the parent." (participant 8)

Although psychological needs may be a barrier, the impact of this could be reduced. For example, by offering mental health support before VIG and continued support after VIG had ended.

"We can also add some other stuff in kind of like emotional regulation work, so if they're very preoccupied and not able to see themselves then it's very hard to attend to your child and very difficult to do VIG, it's hard to be in the moment so sometimes we might do something additional with that, sometimes we realised they might have a trauma history

and so they might need some additional therapy in order to be able to do this.” (participant 7)

The impact of the guider on the intervention.

Guiders’ expectations and assumptions.

The participants recognised how their own assumptions or negative expectations for the intervention were a hindering factor.

“It was the first time working with parents with additional needs, learning needs, I was quite scared because [...] I kind of thought they wouldn’t want the intervention.” (participant 3)

“It’s about expectations I suppose. My expectations I guess, of how successful or not successful it will be. And people’s capacity for change.” (participant 2)

Guiders’ inexperience.

Some guiders identified their inexperience as a hindering factor. One guider explained that VIG training does not include any specific guidance on working with parents with ID, which limited her ability to apply the model effectively. Supervision was valued to help overcome these challenges.

“We don’t know enough about working with parents with additional needs, especially when it’s LD. [...] And I think we need to go further than having photos of workers on letters! That is not only what the parent needs.” (participant 3)

“I think I am developing and I’m still quite a novice at VIG but I think I’m getting better at it. And I think it’s good supervision, I can talk about some of the challenges and my supervisor may come up with a different approach, or just give me the confidence to be a bit more exploratory.” (participant 8)

A model of the impact of VIG with parents with ID and the factors which facilitate and hinder change, from the perspective of VIG guiders

The study aimed to generate a theoretical model to explain the process of change during VIG with parents with ID. The resulting model (Figure 2), based on participants’ accounts, is a diagrammatical representation of the impact of VIG and the factors which facilitate and hinder change. Arrows indicate direction of influence.

Before VIG began, guiders reported that parents with ID tended to have a broadly negative view of parenting and their child. Parents’ confidence in their parenting ability was often low and their parenting skills were described as limited. They were often thought to hold negative expectations for the relationship with the VIG guider, their own ability to participate in the intervention and were concerned about being filmed. These expectations may be grounded in the negative and stigmatised views around ID held in society, and their own previous experiences of being supported. For some parents, these factors contributed to difficulties engaging with VIG, and the guiders worked to allay some of these concerns in order to promote a successful intervention.

Once a parent engages with VIG, the process of change begins. Parents were reported to see themselves interacting successfully and differently on video. This visual aspect of VIG compensates for some of the difficulties with language associated with ID. On watching the video, parents were often described as experiencing positive emotions, which is reinforcing, leading them to repeat the behaviour. Some parents were considered to experience negative emotions, again encouraging repetition of the desired behaviour, perhaps due to cognitive dissonance. Sharing successes with others, often a new experience for people with ID, is also reinforcing. Parents were reported to begin to feel more confidence in their parenting ability, and thus there are more opportunities for positive filmed interactions.

The focus on positive parenting and increasing confidence was thought to contribute to the development of a new, strengths based narrative, contrasting with problem saturated narratives held by and about parents with ID. It was suggested many parents began to conceptualise themselves, their child, and the relationship more positively. As a result, parents are more able to see the successes in the filmed interaction, leading to a positive experience of the second shared review. This change occurred in the context of an attuned therapeutic relationship, with the guider modelling parenting skills and empowering parents.

The change process is reported to contribute to improvements in child development, the parent-child relationship, parenting skills, and the parents' relationship with systems. These outcomes feed back into the process of change: as parenting improves, so does the opportunity for successful filmed interactions. These outcomes are thought to be hindered by both parent and guider intrapersonal factors, as well as interpersonal and contextual

factors. The outcomes can be facilitated by adapting the VIG protocol for parents' learning needs and providing mental health support for parents. Guider's own supervision, a focus on engagement and the social care context can also facilitate the outcomes of the intervention.

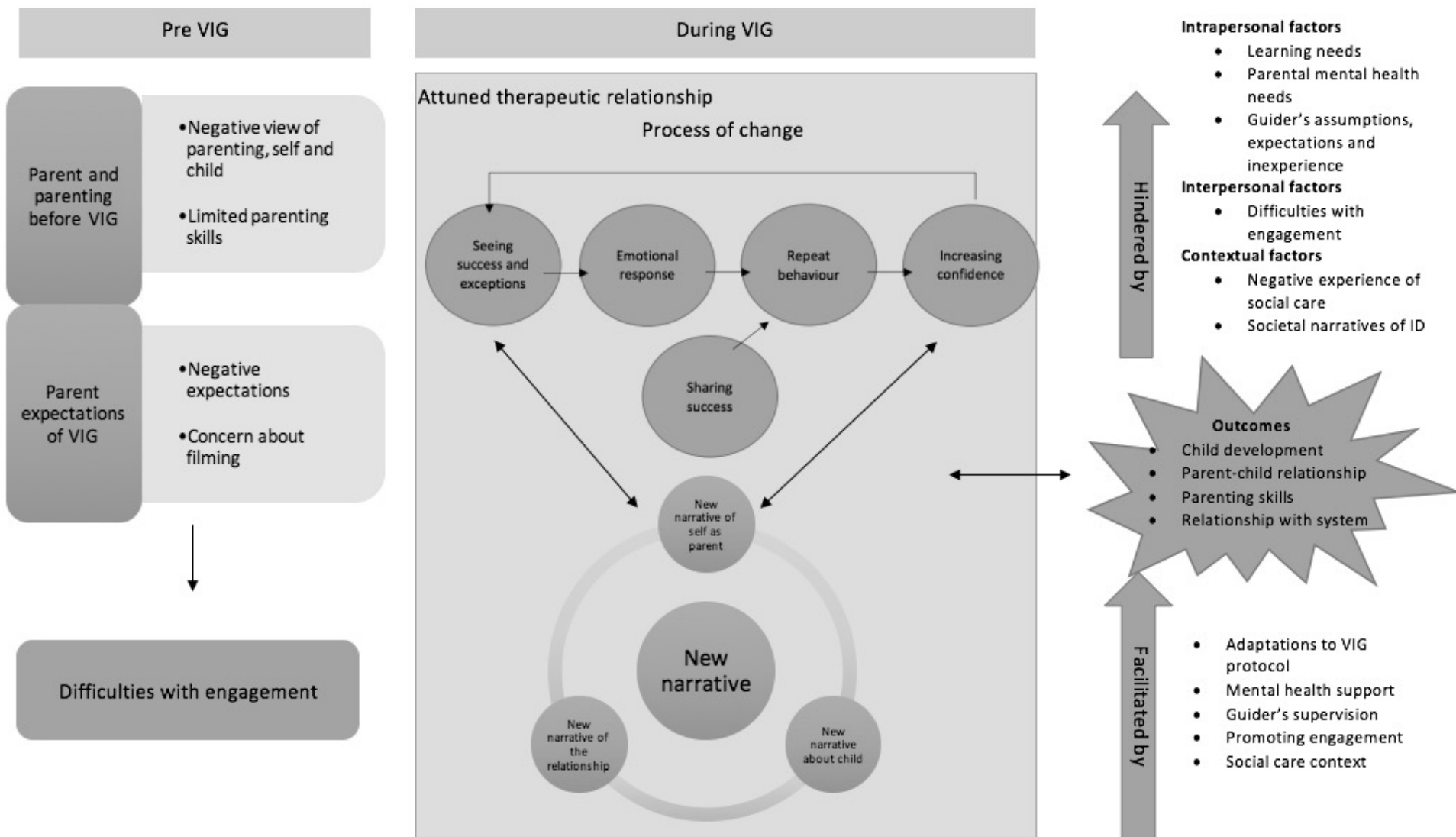


Figure 2. Proposed model of process of change during VIG with parents with ID.

Discussion

Overview of findings

The results of the study show that VIG is reported by experienced guiders to produce outcomes for parents with ID that are largely similar to the outcomes achieved by parents without ID, thus supporting the use of the intervention with this client group. The guiders highlighted factors which facilitated the process of change for parents with ID specifically. The visual aspect of VIG overcame some of the parents' challenges with verbal language, as well as providing evidence of success which could be shared with others and challenged a disabling narrative. Emotional experience, often disregarded in interventions for people with ID, also facilitated the intervention. These factors, in the context of an attuned and empowering relationship, contributed to the development of a new, strengths based narrative. Cognitive difficulties, associated with ID, often made VIG more difficult. The findings identified ways in which this can be compensated for. Similarly, VIG can be adapted to some of the specific challenges parents with ID face in a broader societal context.

The results are discussed in line with the research questions.

What is the impact of VIG when working with parents with ID, from the perspective of VIG guiders?

In line with the finding that parents with ID are able to benefit from evidence-based training programmes (McConnell, Feldman & Aunos, 2017), all participants reported that VIG had some positive impact. Guiders reported positive outcomes for child development, the parent-child relationship, and insight into parenting support needs. Attuned parenting skills

were considered to improve in comparison to parenting skills before VIG. These findings are in line with the outcomes of video feedback interventions identified by Fukkink (2008), suggesting that VIG has a comparable impact for parents with and without ID.

The outcomes of VIG, from the perspective of VIG guiders, are in line with the goals set by parents with ID. Hunter et al. (in prep.) found that parents with ID identified their goals for VIG as improving their communication, child development, development of self, and better relationship with the wider system. The present study suggested these changes were facilitated by VIG. In addition to addressing parents' goals, the present study suggests VIG is also able to address parenting support needs identified in the literature (Emerson & Brigham, 2014). However, some of the concerns identified for children with a parent with ID were not ameliorated following VIG, for example, greater incidence of accidents and injuries (Schuengel et al., 2017). It is not clear from the present research if VIG increases children's safety and thus further research is needed to explore this question.

Parents with ID are often socially isolated (MacIntyre & Stewart, 2012). Following VIG, parents were reported to have a better awareness of their parenting support needs and as a result engaged with services and attended parenting groups, thus decreasing their isolation. Social isolation exacerbates psychological difficulties for people with ID (Bates & Davis, 2004), and support networks help the development of parenting skills, well-being, self-confidence (Gustavsson & Starke, 2017), and reduce the likelihood of maltreatment (James, 2004). In addition, the quality and frequency of social and practical support provided to parents with ID is the best predictor of their parenting competence (McGaw, 1998). It therefore can be hypothesised that a reduction in isolation could improve parental mental

health and promote parenting skills. Hodes et al. (2017) also hypothesise a reduction of social isolation is an important contributor to the success of video interventions with parents with ID. As contextual factors may impact upon the development of a secure attachment, and play a major role in the parenting difficulties experienced by people with ID (Llewellyn & Hindmarsh, 2015) it is promising that VIG may be able to reduce the impact of these factors.

Other research using similar interventions has highlighted outcomes that were not identified in the current study, such as a reduction in parenting stress (Hodes et al., 2017). Participants in the current study did not discuss parenting stress, meaning conclusions about the relationship between VIG and parenting stress cannot be drawn. As parents with ID have significantly higher levels of parenting stress (Meppelder, Hodes, Kef, & Schuengel, 2015), and parenting stress is associated with child behaviour problems (Feldman, Varghese, Ramsay, & Rajska, 2002), further research exploring VIG's impact on parenting stress for parents with ID is indicated.

However, despite all participants discussing the positive impact of VIG, there were occasions when VIG was not able to facilitate change, and children were removed from their parents' care. Further research is required to explore the conditions under which VIG is less effective for parents with ID, and whether these conditions can be ameliorated.

What are the factors that facilitate or hinder VIG with parents with ID, from the perspective of VIG guiders?

The analysis identified factors which were considered by VIG guiders to both facilitate and hinder the outcomes of VIG when working with parents with ID. Some of these are in line with the evidence exploring the use of VIG with parents without ID, and some are likely to be unique to the ID population.

Engagement.

Some parents were considered to hold negative expectations for the intervention which made it difficult to engage. People with ID have often had support from a range of health professionals, and thus bring these experiences into new therapeutic relationships, impacting engagement (Fidell, 2000). Further, participants noted that their lack of experience and service demands made it difficult to engage harder to reach parents, meaning arguably the neediest parents were not supported to access the intervention.

Although engagement may be difficult, the current study and the literature suggests people with ID can engage in psychological therapies (Willner, 2005). Fidell (2000) argues that a collaborative stance, rather than an expert one, is important for engaging people with a negative expectation of therapy. In line with this, participants reported that the development of a collaborative and secure therapeutic relationship, often a new experience for people with ID, facilitated engagement. This stance complemented VIG's strengths-based approach, which allayed concerns about filming.

The process of change and a new narrative.

Participants highlighted processes of change that may facilitate the success of the intervention. The visual aspect of VIG, parents seeing themselves engaging positively with their children and seeing exceptions to parenting as usual, was thought to promote change. The video provides evidence of this change, which is particularly important for a population often defined by their limitations (Dawes, 2011). The importance of the visual aspect is in line with Doria et al. (2014), suggesting methodological components of VIG which facilitate change with parents without ID are also important for parents with ID. However, for parents with ID, the visual aspect is likely to further support the intervention by overcoming some of their challenges with language. This is supported by Ward and Tarleton's (2007) suggestion that interventions for parents with ID should use visual methods, such as video recording, to develop parenting skills.

From the perspective of VIG guiders, change was further facilitated by an emotional response to video clips, as found in previous research with parents with ID (Hunter et al. in prep.) and parents without ID (Doria et al., 2014). Participants suggested that the positive emotions parents experienced while watching themselves interacting with their child encouraged them to repeat the behaviour, through classical conditioning principles (Simonov, 2003). In contrast to Hunter et al. (in prep.), participants in the present study discussed how the experience of negative emotions also facilitated change. It can be hypothesised that participants were experiencing cognitive-dissonance (Festinger, 1962) between the parenting behaviour they saw on film, and their perception of good parenting. This experience may have led to psychological tension, demonstrated by negative emotions during the shared review. The parents were motivated to reduce this distress, and as such,

changed their parenting. This is in line with hypothetical mechanisms of change discussed by Doria et al., 2014. However, both Doria et al. (2014) and the present study only tentatively support this hypothesis and further research is needed to explore cognitive dissonance as a mechanism of change.

While there is a rhetoric that people with ID have limited access to their emotions, emotional experience was thought by guiders to be an important contributor to change during VIG. Similarly, Tarleton and Wade (2007) found parenting interventions with parents with ID were facilitated by emotional support. However, professionals working with people with ID have historically neglected their emotional lives (Arthur, 2003). Therefore, in order to aid the intervention, VIG guiders should attune to and mentalize the emotions of parents (Kennedy, Landor, & Todd, 2011).

Positive reinforcement from others, using operant conditioning principles, was identified by participants as facilitating VIG. This is in line with McGaw and Newman's (2005) suggestion that interventions for parents with ID should include praise. In narrative therapies, sharing successes with others, known as outsider witnessing, helps a new narrative to take root in a person's life (Carr, 1998), and has been found to be an important element of narrative work with people with ID (McParland, 2015).

From a narrative perspective, difficulties are maintained when exceptions to problems are minimised, and change occurs when alternative, strengths based narratives are thickened (Harper & Spellman, 2006). The development of a new narrative about the self, their child, and the relationship was considered to be important factor which facilitated the

intervention, supported by Hunter et al. (in prep.) Therefore, VIG guiders working with parents with ID should strive to incorporate elements of narrative therapy into the intervention, and thicken the developing strengths-based narrative in order to promote behaviour change. This could be achieved by focusing on exceptions in the video and externalising parenting challenges (Carr, 1998), as well as supporting parents to share their success with others.

An attuned therapeutic relationship distinguishes VIG from other video-feedback approaches (Kennedy et al., 2010), and was identified as an important factor in facilitating change. This is in line with findings from studies of parents with ID (Hodes et al., 2017; Hunter et al., in prep.) and without ID (Doria et al. 2014). As parents with ID have often been exposed to neglectful or traumatic experiences of being parented (Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014) it can be theorised attunement is a new experience, reinforcing the importance of offering attachment based interventions to this client group. The therapeutic relationship was also used to empower parents, in line with government commitments to promote empowerment for people with ID (DoH, 2001). It is notable that the empowering nature of the relationship was not discussed by Doria et al. (2014) and it may be that the importance of empowerment is more notable in an ID population.

The processes of change discussed shares similarities with Doria et al.'s (2014) findings, suggesting that, from the perspective of VIG guiders, VIG works in a similar way for people with and without ID, promoting the use of VIG with this group. However, Doria et al. (2004) emphasise that meta-cognitive processes underlie the success of VIG for parents without ID. Although the current research found parents with ID do reflect during the intervention, the

visual aspect, emotional response, attuned therapeutic relationship and positive reinforcement were considered to be the key elements of change, rather than meta-cognitive processes. This has implications for guiders working with parents with ID, and thus highlights the importance of researching VIG with parents with ID specifically.

Adaptations for ID.

A further departure from the evidence base, and thus a novel finding, is the identification of ID specific factors which are thought to hinder the intervention. In order to be effective, interventions for parents with ID need to make adaptations for their specific needs (Hodes et al., 2014).

In order to compensate for verbal difficulties, participants used simple language and often used the parents' own language. In addition, participants used visual stimuli to aid parents understanding of concepts such as attunement. These adaptations have been found to be helpful in therapeutic interventions with people with ID (McGarry, Stenfert Kroese, & Cox, 2016; Whitehouse, Tudway, Look, & Kroese, 2006).

Participants used concrete learning tasks to help parents consolidate their learning, compensating for difficulties with memory and abstract thought. For example, one participant described adding speech and thought bubbles to stills from the film, drawing upon Gray's (1994) comic strip conversation approach. Although this method was originally developed for children with autism, it has proved helpful for people with below-average verbal ability (Glaeser, Pierson, & Fritschmann, 2003). However, the approach has not been

researched in parenting interventions with parents with ID and thus conclusions about the utility of the approach are tentative.

Participants reported that they adapted the intervention by using repetition, having more sessions, and going more slowly. This, guiders felt, allowed for processing speed difficulties and increased parents' understanding of the intervention. This suggestion is supported by Hunter et al.'s (in prep.) finding that parents with ID report they often found VIG sessions too long. The participants also modelled parenting skills, a useful element in parenting interventions with parents with ID (Ward & Tarleton, 2007).

Some parents were described as having limited insight into their parenting needs and overestimated their parenting skills, leading some to disengage. Professional concern about parental insight is associated with children being placed into care (Booth et al., 2004). When participants were able to encourage parents to reflect on the difference between the video and their typical parenting, their insight was reported to increase. This encouraged some parents to engage in other forms of parenting support.

Difficulties generalising during VIG, a common barrier for parents with ID (Heinz & Grant, 2003; Wade et al., 2008), questions the ecological validity of the intervention. To promote generalising, participants suggested parents should receive VIG across a variety of settings, and in the environment in which the skills are needed (McGaw & Newman, 2005). In addition, generalising was facilitated by direct discussion of the need to generalise. Although this deviates from the VIG protocol, which values reflection as the process of

behaviour change (Kennedy et al., 2011), direct encouragement for generalising has been found to facilitate change during VIG with parents with ID (Pethica & Bigham, 2018).

However, while the results suggest adaptations can compensate for learning needs, these should match the level of understanding and preferred approach of each parent (McGaw & Newman, 2005). This is highlighted by some parents finding the use of pictures patronising. As such, VIG guiders should strive to formulate parents' individual needs, and use appropriate adaptations for each parent (WTPN, 2016).

Contextual factors.

The participants discussed negative stereotypes and assumptions held about parents with ID in society (Espe-Sherwindt & Crable, 1993), which implied they would be incompetent parents (Gould & Dodd, 2014; Theodore et al., 2018). This was thought to impact upon the intervention as some parents took a passive approach, perhaps internalising these narratives. The importance of VIG guiders empowering parents is highlighted.

Another contextual factor which impacted on the intervention was parents' involvement with social care (Booth & Booth, 2005). Social care had the potential to promote engagement, and allowed guiders to focus on the intervention rather than managing risk. However, social care also hindered the intervention. In line with the literature (for example, Booth & Booth, 2005) parents were often reported to experience social care as scary and judgemental. This experience was thought to translate into VIG, making it difficult to establish a therapeutic relationship and leading some parents to mask their difficulties. Similarly, Hunter et al. (in prep.) found some parents did not acknowledging their role in

contributing to their child's difficulties, and therefore were resistant to change. In order to facilitate the intervention, guiders could reflect with parents about their experience of social care, and formulate the impact of this on the intervention.

Individual differences.

Both guider and parent individual differences were considered to hinder the intervention. People with ID experience high levels of childhood abuse, trauma and maltreatment (Granqvist et al., 2014) and mental health difficulties in adulthood (Cooper, Smiley, Morrison, Williamson, & Allan, 2007). Indeed, parental mental health has been found to have a greater effect upon parenting than IQ (Sterling, 1999). Mental health needs contributed to parents' difficulties attuning to their children. VIG guiders can reduce the impact of parents' psychological needs by ensuring mental health support is provided before or alongside VIG. In addition, VIG guiders should be mindful that parents with ID may have undiagnosed mental health needs, as screening tools for post-natal depression are less reliable in this population (Gaskin & James, 2006).

In support of Taylor's (2016) assertion that VIG guiders impact upon the intervention, participants identified their own negative expectations and their inexperience working with parents with ID as a hindering factor. Worryingly, many professionals hold stereotypical assumptions that parents with ID cannot parent (Cleaver & Nicholson, 2007). The importance of VIG supervision when working with hard to reach parents is recognised by Kennedy et al. (2010), as is the need for supervision in supporting inexperienced professionals working with parents with ID (McGarry, Stenfert Kroese, & Cox, 2016). Participants reported supervision helped to build their confidence.

In summary, the findings show that VIG is reported by VIG guiders to produce outcomes for parents with ID that are broadly similar to the outcomes found in the evidence base for video interventions with parents without ID. There are both similarities and differences in the process of change during VIG with parents with and without ID, and thus guiders should focus on the factors which have been found to facilitate VIG specifically with parents with ID. Further, VIG can be adapted to overcome some of the specific challenges parents with ID face with their learning needs, mental health, and in a broader societal context.

Clinical implications

The findings highlight that conducting VIG with parents with ID poses some unique challenges. Some guiders felt inexperienced to work with this client group, and thus AVIGuk training should support guiders to work with parents with ID.

In order to deliver VIG in a sensitive and effective way, guiders should strive to promote the factors which facilitate the intervention, make appropriate adaptations to the protocol, and limit the hindering factors. For example, VIG guiders should strive to allay parents' fears and concerns about the intervention. They should develop a collaborative and empowering therapeutic relationship, focusing on the visual content, encourage emotional expression and share successes with others. They should strive to thicken a strengths based narrative. While conducting VIG, guiders should use visuals and concrete learning tasks, and adapt their language and pace to suit the parents' needs. They should strive to promote generalisation and evaluate outcomes using appropriate measures. Parents should also be provided with mental health support, and their experiences with social care should be considered. Services which use VIG should also provide supervision, and space for guiders to

reflect on their own expectations and assumptions for their work with parents with ID. See Appendix 17 for a summary of these clinical recommendations.

The development of a new strengths-based narrative was considered to be an important process of change for this group, and contrasted to narratives held about parents with ID in society. Practitioners who support parents with ID using a range of modalities should draw upon a strengths focused approach in their work, emphasising stories of competency (Baum, 2007) and empowerment (DoH, 2001).

Until recently, the role of attachment theory has been neglected in the lives of people with ID. A broader clinical implication of the study is support for the British Psychological Society's (BPS; 2017) recommendation to incorporate attachment theory into therapeutic work with people with ID. The findings from the current study and the wider literature suggest both parents with ID and the people who support them value the use of attachment based interventions, and thus services should strive to incorporate this approach.

Strengths and limitations

A strength of the study is its originality and rigour, including the use of in-depth interviews. The study builds upon case study (Pethica & Bigham, 2018) and brief interview (Hunter et al., in prep.) research exploring the use of VIG with parents with ID. The research also addresses limitations in Doria et al.'s (2014) study by highlighting factors which hinder VIG's success and exploring the impact of individual differences. It is hoped that a richer understanding of the factors which facilitate and hinder change will increase the effective use of VIG with parents with ID.

Another strength of the study is its adherence to quality standards for qualitative research (Elliot et al., 1999). The researcher outlined their own perspective, both professional and personal, and used a reflective log to 'bracket' these assumptions. Participant demographics were provided to situate the sample, and direct quotations were used to ground the results in examples. Various forms of credibility checks, such as a second reviewer and respondent validation, were used and have been identified as an important way to ensure rigour in grounded theory research (Cooney, 2011). However, the researcher had prior knowledge of the process of change during VIG which may have impacted upon the results (Glaser & Strauss, 1967).

The study was conducted at several sites over a wide geographic area. This meant a range of perspectives could be gained, such as accessing a service which specialised in the use of VIG with parents with ID. Therefore, a strength of the study is the heterogeneity of the sample, facilitated by the use of Skype (Janghorban et al., 2014). Charmaz (1996) argues grounded theory research at multiple sites has greater generalisability compared with other qualitative methods.

However, the use of Skype was also a limitation of the study. Research suggests the ability to establish rapport and read non-verbal cues is reduced over Skype (Seitz, 2016), limiting the researcher's ability to gather rich data. There were also occasional difficulties with the video stream and clarity of the audio which impacted on verbatim transcription. However, the researcher felt that it was possible to establish adequate rapport with the majority of interviewees, supported by Janghorban, Roudsari, and Taghipour (2014). The interviews using different modalities were of a similar length and supplied comparatively rich data,

supported by direct comparison of telephone with face-to-face interviews (Carr & Worth, 2001).

Another limitation of the research are the deviations from the grounded theory methodology. Due to participants' availability, it was not possible to complete initial coding of each interview before conducting the next and therefore the researcher's ability to collect and analyse data in parallel (Sbaraini et al., 2011) was limited. Further, due to small numbers of VIG guiders working with parents with ID, it was not possible to use theoretical sampling. Theoretical sampling allows researchers to select participants that will allow them to explore areas of interest, clarify uncertainties and test interpretations while building their emerging theory (Sbaraini et al., 2011). To compensate for these limitations, the researcher reflected on what they had heard after each interview and adapted the interview schedule to test out emerging themes (Charmaz, 2006). This allowed the researcher to highlight gaps in the existing data set (Sbaraini et al., 2011), although the rigour is likely to be reduced compared to the traditional grounded theory methodology.

The study's relatively small sample size and lack of theoretical sampling make claims that the study reached data saturation (Glaser & Strauss, 1967) or sufficiency (Dey, 1999) unconvincing, which is a further limitation of the research. However, Guest, Bunce, and Johnson (2006) found that the majority of high frequency codes were identified through analysis of six research interviews, with new codes emerging after this point often variations on existing themes. Further, fewer research participants are needed when they have a high degree of competency in the area of interest and when structured questions are used to

explore knowledge, rather than focusing on individual experiences of phenomena (Romney, Weller, & Batchelder, 1987). These criteria are met in the current study. Therefore, it is arguable the current study had enough participants to achieve the research aims and the use of nine participants in this study is not, of itself, indicative that theoretical sufficiency was not achieved.

Another limitation is the use of proxy reports of ID from participants (Brooker et al., 2015). While this meant the sample was inclusive of the 'hidden majority' of parents with learning needs who do not access ID specific services (Emerson, 2011), it is not possible to draw firm conclusions about the impact of IQ on VIG. Further, the replicability of the sample is compromised.

Finally, this research privileged the voice of VIG guiders. The participants are presenting their understanding of parents' experiences of VIG, which cannot be assumed to reflect parents' own experiences. However, as there are broad similarities to Hunter et al.'s (in prep.) exploration of the experience of VIG from the perspective of parents with ID, it is arguable the present study holds relevance for this client group. Further, as the participants were discussing their own work, they may have given positively biased responses and described their interventions as successful. This may have contributed to a limited discussion, lacking nuance, of the challenges of using VIG with parents with ID. However, while social desirability bias is a common phenomenon in quantitative research (Nederhof, 1985) there is limited evidence for the emergence of this bias in qualitative methodologies (Collins, Shattell, & Thomas, 2005), and thus should not be assumed in the current research.

As such, as is often the case in qualitative research, readers should remain mindful that the results represent the construction of a reality by both the participants and researcher (Charmaz, 2006).

Future research

The current research highlights the utility of VIG with parents with ID. Future research could systematically evaluate the factors which have been identified as facilitating the intervention. For example, one group of parents with ID could receive VIG as usual, and another group could receive a formally adapted version of VIG based on the learning from the current study. The perspectives of parents and guiders could be explored. This would increase understanding of how the adaptations described in the current study are experienced, for example whether an adapted version of VIG is experienced as increasing parents' competence (Thomas & Harden, 2008).

Participants discussed that parents were often receiving packages of care, and thus further quantitative research could use a RCT methodology to differentiate the outcomes of VIG and the impact of treatment as usual. This would help to highlighted specific aspects of VIG which is beneficial to parents with ID.

Another avenue for future research is to use quantitative assessment of outcomes as a method of triangulation (Mays & Pope, 2000). VIG could be conducted with parents with ID, using the learning from the current study, and quantitative outcomes could be measured. A body of evidence drawing on both qualitative and quantitative methods increases the likelihood of influencing clinical practice (Östlund, Kidd, Wengström, & Rowa-Dewar, 2011).

The current study and Pethica and Bigham (2018) found the standardised VIG outcomes measures were poor at capturing change when working with parents with ID. Future researchers could adapt outcome measures, co-produced with parents with ID (Bowers & Wilkins, 2012) in order to privilege their voices.

Conclusion

VIG is an appropriate intervention for parents with ID. VIG guiders suggest it contributes to outcomes which are in line with the needs and goals of parents with ID, and are comparable to parents without ID. This suggests that the outcomes described in the evidence base exploring video interventions for parents without ID hold relevance for this client group.

There are a range of factors which facilitate and hinder the process of change for parents with ID specifically which can guide practitioners in effective and sensitive implementation of the model. The visual aspect of VIG, an emotional response and positive reinforcement contribute to the development of a new narrative, which contrasts to disabling narratives and presumptions of incompetence (Gould & Dodd, 2014; Theodore et al., 2018) often held about parents with ID. This change occurs in the context of an attuned and empowering therapeutic relationship, which is often a new experience for parents with ID. Parents' learning needs, associated mental health difficulties and the social care context impacted upon the intervention, making it more challenging at times. VIG guiders suggest that adaptations to the VIG protocol, and supervision which allows guiders to reflect on their inexperience and assumptions, can overcome some of these challenges and promote change.

As the evidence base and professional support for the use of attachment based interventions for parents with ID grows (BPS, 2007) it is hoped an increasing number of parents with ID will receive interventions which focus on their own and their children's attachment needs, and they will increasingly be supported to raise their own children.

Paper 3: Integration, impact and dissemination

The following section is an evaluation and critical appraisal of the overall research process. It outlines the integration of the systematic review and empirical paper, the potential impact of the research and plans for dissemination. The researcher's own reflections throughout the process are also discussed.

Integration

Interest in the topic area.

My interest in the topic area began as an interest in parenting interventions and attachment theory. My pre-training employment involved providing interventions for parents of children with disabilities. Some of the parents I worked with in this role had received VIG from other members of the team, and I was struck by how passionately they spoke about the intervention. They often wanted to show me stills from the videos and smiled while they did so. On clinical training, my academic teaching and clinical placements highlighted to me the marginalisation people with ID experience, and I was shocked to learn women with ID had been forcibly sterilised across the world as recently as the 20th century (Tilley, Walmsley, Earle, & Atkinson, 2012). On my placement with adults with ID, I was struck by a woman who reported to me she wanted to become pregnant, but the notes on the system recorded by community nurses highlighted they were advocating the use of contraception, and ignoring her wishes. A general theme at the service seemed to be one of infantilising and disregarding the sexuality of adults with ID.

As I began to read around the topic area, I learnt that the relationship between ID and parenting skills is not causal (Llewellyn & Hindmarsh, 2015) and contextual factors play a

significant role in parents with ID's ability to parent effectively (Schuengel, Kef, Hodes, & Meppelder, 2017). I was also surprised that despite attachment based video interventions being recommended by The National Institute for Health and Care Excellence (2012) to promote social and emotional wellbeing in the early years, the majority of parenting interventions offered to parents with ID emphasised learning practical parenting skills, rather than focusing on the parent-child relationship (Coren, Thomae, & Hutchfield, 2011; Wade, Llewellyn and Matthews, 2008). Bakermans-Kranenburg, van Ijzendoorn and Juffer (2003) found parenting sensitivity, a precursor to a secure attachment, requires an intervention with a focus on sensitivity. This evidence seemed to be being neglected in support offered to parents with ID.

As such, my interest in the topic area was born. There had been some preliminary research exploring the use of video interventions with parents with ID, but I wanted to explore the factors that improved or were detrimental to the experience of the intervention, and ultimately outcomes, for parents with ID. My motivation was mainly application – how can VIG be delivered in a way which promotes parents' competence and improves outcomes for their children?

In order to situate my empirical paper, I felt a systematic review of how parents experienced the support they received more broadly would provide a backdrop to VIG as an alternative way of supporting parenting with ID.

Changes to the sample.

Originally, my proposed empirical paper included interviews with both parents with ID and professionals. I was really keen to capture the voices of both groups, as the voices of parents with ID are often subjugated in research (Department of Health, DoH, 2015), and I felt this would provide valuable insights into the experience of VIG. However, both practical and theoretical barriers emerged to this proposition. Firstly, the numbers of parents with ID receiving VIG is small, and thus recruitment difficulties were anticipated. A specialist service offering VIG were happy to support recruitment of their service users, but the rural setting, and my lack of driving licence, meant this was unfeasible. Secondly, I discovered that Hunter, Murphy, Black, and Hockaday (in prep.) had recently explored the views of parents with ID who had had a VIG intervention. I was really disappointed by the prospect of only interviewing professionals, but supervision helped me to reflect on the practical and theoretical benefits of recruiting professionals only.

The loss of the parents' voice from the empirical paper furthered my interest in using the systematic review, and feedback from service users, to understand parents' perceptions of the support they receive, and I am pleased to have been able to achieve this. Further, I noted lots of participants in the empirical paper spoke using the words of parents, and reported on parents' experiences. Of course, this is a professional perception of parents' experience, but it highlighted to me that the participants cared about and considered the experience of the parents they supported. Their desire to mentalize the parents, a key element of VIG (Kennedy, Landor, & Todd, 2011), seemed to continue long after the intervention had finished.

Keeping a reflective journal.

Throughout the process, I kept a reflective journal to help me 'bracket' my own knowledge and values from impacting upon the research (Elliot, Fischer, & Rennie, 1999). This felt particularly important due to my pre-existing theoretical knowledge of VIG, practical knowledge of working with parents with ID, and familial relationship with a woman with an ID. This process highlighted to me my changing perceptions of people with ID. When I began the research, although I didn't realise it at the time, I unwittingly subscribed to what Goggin (2009) described as the 'charity model' of disability. This model, regarding people with disabilities as vulnerable and in need of special care or treatment, limits the personhood of people with ID by focusing on limitations rather than strengths. This message is unfortunately perpetuated in the media, and at times by members of my own extended family.

The use of a reflective log allowed me to notice this perspective, and thus reduce its influence on the collection and analysis of data in both research projects. I aimed to maintain a neutral stance when writing up the results in order to accurately represent what I heard from participants. As a result of the research process, I now subscribe to an affirmative approach towards disability (Fitch, 2002), highlighting individuality, strengths and capacities. This is a stance I hope to endorse in my dissemination.

Ontological and epistemological positioning.

The research process encouraged me to consider the epistemology on which the research is based. Both the systematic review and empirical paper are based in a constructivist

framework, regarding reality as open to some interpretation and construction. This is in line with the stance of VIG (Kennedy, Ball, & Barlow, 2017) and the grounded theory approach (Charmaz, 2006). However, at times during the data collection and analysis for the empirical paper, I found myself swaying towards a positivist epistemology. On reflection, I think this was due in part to the fact that I interviewed professionals, who are often considered experts in their field. Both the reflective log and credibility checks helped increase my awareness of this waver towards positivism. For example, one participant responded that the model fitted with her experiences, but reminded me that individuals' experiences are likely to vary significantly. As a result of this reflection, I revisited the narrative description of the model and the discussion, and hoped to have demonstrated my constructivist stance.

Challenges of the systematic review and empirical paper.

A major challenge in conducting the systematic review was my inexperience in the approach. I became aware of debates around reviewing qualitative data which I needed to make decisions about, but at times I felt ill informed to do so. For example, there is a debate around the utility and appropriateness of assessing the methodological quality of qualitative studies (Carroll & Booth, 2015; Toye, Seers, & Barker, 2017). Although I understood this debate from a theoretical perspective, I only gained experiential knowledge of the difficulties of using checklists such as CASP (2018) once I had begun the process. If I were to repeat the systematic review, I would adapt the checklist to make it more applicable for my research question, such as rating whether parents' perspectives were prioritised over researcher interpretations.

Another challenge in the systematic review was deciding what constitutes parenting support. I wanted to understand how parents with ID experienced the broad range of support they receive, as many parents with ID receive a package of care from multiple providers (Working Together with Parents Network, WTPN; 2016). Supervision aided these decisions, for example the inclusion of advocacy support. However, the variety of types of support experienced made data synthesis challenging, and I feel that while the results have breadth, they lack some depth. Using Thomas and Harden's (2008) model of competence promoting and inhibiting support helped me to make sense of my findings, although this might have made the discussion of the results more deductive and less grounded in the data.

A major challenge of the empirical paper was data analysis, given that I had not reached data saturation. The in-depth interviews generated huge amounts of data. Although as I coded successive interviews, I generated a decreasing number of new themes, it was not always clear which themes were the most important or most significant. I found myself making intuitive decisions about the importance of themes, perhaps due to how much they resonated with my knowledge of VIG and parents' with ID, rather than because the theme had been saturated. However, the credibility checks from staff helped me to ensure that the resulting model resonated with their experiences.

Reflection on the findings of both studies.

There are several similarities, and also differences, in the findings of the systematic review and empirical paper. A common theme across both papers is the emotions associated with

receiving and giving parenting support. The empirical paper highlighted that during VIG, a positive or negative emotional response contributed to the repetition of positive parenting skills. Although not captured in the final model, I was also struck by the emotion and passion with which participants spoke about their work. This passion motivated me throughout a research process that at times felt arduous.

In the systematic review, the parents themselves spoke about valuing emotional support for their parenting, and also the frustration, anger and humiliation they experienced when their emotions are disregarded. I was reminded of Arthur's (2003) comment that professionals often shy away from supporting the emotional needs of people with ID, and I hope to capture the importance of this in my dissemination. Reflecting on the passion and emotion in the research, the value of a qualitative approach was reinforced for me. While having other benefits, I doubt a quantitative piece would have been able to capture the rawness of emotional experience.

Another similarity in the research pieces is the narratives surrounding disability. From both the perspective of parents and VIG guiders, parents often have to contend with disabling narratives and a presumption of incompetence (Gould & Dodd, 2014). In the empirical paper, the development of a strengths-based narrative was a central process of change. Although not explicitly named in the systematic review, the experience of support as empowering suggests that a new narrative, focused on ability, was emerging for parents.

However, concurrently with the early phases of the research process, I conducted a narrative intervention with a woman with ID. I found the approach incredibly powerful and appropriate for this client group, and have since incorporated narrative therapy in to a lot of my clinical work. Reviewing my reflective journal, I noticed that I did not reflect on this explicitly, and I wonder if I appropriately bracketed my preference for a narrative approach. In order to address this, my credibility checks asked participants to feedback on whether they felt that a changing narrative was an essential part of their work. All of the participants who fed back on the model agreed its importance, and thus I hope my approach did not bias the results of the empirical paper.

The findings of the studies also highlighted areas of discordance, which reinforces the benefit of collecting data from both parents and professionals. Most notably, the empirical paper highlighted that before the intervention began, parents had limited parenting skills, and a negative view of their parenting ability. In contrast, the systematic review found that parents did not feel that they had limited parenting skills, felt support often did not meet their needs and focused on skills they felt they already possessed. It may be that VIG guiders were approaching the intervention with preconceptions of parents' limitations. Therefore, a thorough assessment, focusing on strengths, is a clinical impact of the research.

There were some findings in the systematic review which surprised me. I anticipated the experience of parenting support to be generally negative. Perhaps this was due to my bias towards VIG, having spent hours listening to and transcribing interviews which mainly advocated for its use. However, many parents reported they had had positive and

empowering experiences with supporters. Again, the use of the reflective log helped me to become aware of this bias, and thus avoid over emphasising the negative experiences reported by parents.

Overall, both studies extend the evidence base suggesting that parents with ID can benefit from interventions for their parenting. The systematic review highlights that parents experience support both positively and negatively, in line with Thomas and Harden's (2008) assertion that the provision of support alone is not enough to promote parents' competence. The empirical paper extends the knowledge of video interventions with parents with ID, suggesting several factors which can facilitate outcomes.

Impact

Impact is defined by the Research Excellence Framework as 'an effect on, change or benefit to the economy, society, culture, public policy or services, health, the environment or quality of life, beyond academia' (Penfield, Baker, Scoble, & Wykes, 2014). Both the empirical paper and systematic review highlight implications which could have an impact for individuals and their families, and the broader society they live in. I will discuss the implications of the research on various societal 'systems', and reflect on how this has impacted upon my view of the role of a clinical psychologist.

Impact can be considered from the ecological systems perspective (Bronfenbrenner, 1992). Bronfenbrenner's (1992) model uses a four-level framework to conceptualise the complex systems that may impact on an individual's wellbeing (see Figure 3). The micro-level consists

of the individual and their family and accordingly interventions include individual or family therapy. At the meso-level, interventions include members of an individual's community. The exo-system, the larger social network, can be impacted upon by interventions such as professional training and adaptations in organisations. Finally, the macro-system includes cultural values, customs and laws, and interventions at this level include policy change and public health initiatives. The model was originally proposed in a developmental context, but is also applicable to the possible roles of clinical psychologists (Browne, 2017). Using this approach to understand the impact of research is in line with a social and contextual, rather than medical, model of disability (Vertoont, 2018), and acknowledges that prejudices against people with disabilities exist at all levels of the system (Müller, Klijn, & Van Zoonen, 2012). Further, planning for impact at these different levels increases the likelihood the impact will have significance and reach (Penfield et al., 2014).

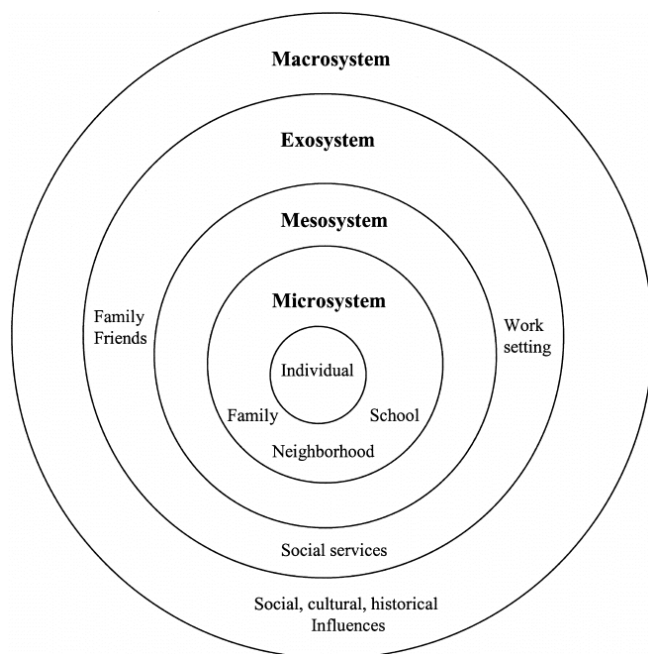


Figure 3. A graphical representation of Bronfenbrenner's (1992) ecological systems theory.

Micro-level: changing the lives of individuals and families.

Both studies highlight the potential to have impact at the micro-level, with individuals and their families. The results suggest that both VIG and other parenting support can benefit parents with ID. However, the range of experiences highlighted by the systematic review, both positive and negative, indicate that the provision of support alone is not enough to promote parenting competence or have positive outcomes for the child (Thomas & Harden, 2008), and thus consideration into how support is provided and experienced is required.

There are numerous guidelines for supporting parents with ID at the micro-level (for example, WTPN, 2016; McGaw & Newman, 2005). However, these are not routinely implemented in adult ID services across the UK (Theodore et al., 2018), and the policy-implementation gap is a well-recognised phenomenon (Rosli & Rossi, 2014). The current studies highlight the need to follow these guidelines in order for individual support to have a positive and competency promoting impact on parents with ID.

People with ID are often exposed to disabling narratives by their personal networks and communities (Vertoont, 2018). The systematic review highlighted that parents were often exposed to a presumption of incompetence, and participants in the empirical paper spoke of both their own assumptions, and those within society, about the capacities of people with ID to parent. Therefore, at the individual level, altering the disabling narratives of the people who support parents with ID could impact upon parents' self-esteem, and thus their quality of life (Morris, 1991). This could be achieved by using therapeutic interventions drawing on narrative theory and techniques (Carr, 1998).

Meso-level: increasing inclusion in communities.

At the meso-level, both studies highlighted that parenting support has the potential to reduce social isolation. Social isolation is known to be associated with an increased risk of maltreatment and neglect (Ceballo & McLoyd, 2002), and parents with ID are some of the most isolated parents in our communities (Llewellyn, Mayes, & McConnell, 2008).

Therefore, offering parenting support to parents with ID has the potential to reduce social isolation and thus impact on the quality of life of both parents and their children (Hall, 2009). This could be achieved by offering parenting support in a group format.

Exo-Level: Economic saving and systems change.

Parents with ID are disproportionately likely to have their children removed from their care (Booth, Booth, & McConnell, 2004), which has significant economic costs. In 2012-2013, local authorities spent £6.9 billion on children's social care (Department for Education; DfE, 2014). In times of austerity, local authorities are under pressure to reduce their spending, and funding to support birth parents to care for their own children has the potential to achieve this goal, as well as improving quality of life. The systematic review highlights that parenting support can be experienced as promoting parenting competence, and the empirical paper is part of a body of evidence suggesting that parents with ID are able to benefit from interventions to support the attachment needs of their children.

Therefore, supporting parents with ID to take care of their children has the potential to have a positive economic impact, and a positive impact on quality of life for parent and child. This could be achieved by making changes to the workings of public systems. For example, social workers could receive training about parents' capacities to parent, rather than focusing on

limitations and vulnerabilities. This could help them realise the feasibility and benefit of parents with ID remaining the primary carers of their children.

Macro-level: Working with policy makers and the media.

The potential for psychologists to intervene at a macro-level is increasingly being recognised (Browne, 2017) and the findings from both papers have implications for national policy, which could have positive benefits for parents with ID. While WTPN (2016) policy makes many important recommendations for working with parents with ID, there is limited reference to the importance of parent-child relationships, and the role of attachment theory is not discussed. In line with British Psychological Society (BPS; 2017) recommendations to incorporate attachment theory into work with parents with ID, psychologists should strive for this to be recognised in government policy. Further, policy could ensure parenting assessments are less punitive, and focus on parents' strengths (British Psychological Society, 2011). Policy impact is facilitated by the inclusion of an executive summary, which makes the research accessible for policy makers.

In addition to policy work, impact at the macro-level includes changes in cultural values and stigma. Parents with ID are often exposed to stigmatising dominant narratives (Baum & Burns 2007), supported by the results of both studies and service user feedback. In order to improve quality of life, there is a need to reduce stigmatised views towards parents with ID. However, this is notoriously difficult (Morris, 1991). One potential method of reducing stigma is through depictions of the romantic lives of disabled people in the media, for example TV programmes such as 'The Undateables'. However, analysis of tweets in

response to the programmes found that negative stereotypes in relation to disability, dating and romantic relationships were reinforced (Vertoont, 2018). Therefore, reducing stigma using the media requires careful consideration of how these messages will be received by the public, and representation of disabled people in less stereotypical and more nuanced ways (Vertoont, 2018). Altering narratives at the macro-level complements changes in narratives discussed at the micro-level. Therefore, to truly change the lives of people with ID, psychologists can work effectively at all levels of the systems described.

Impact differs from benefit, and Penfield et al. (2014) note that research has the potential to produce a harmful impact. Both of the current research projects focused on parents' learning needs, and suggested that these needs can be adequately adapted for and supported. However, parents with ID face a myriad of contextual difficulties which impact upon their parenting (Schuengel et al., 2017) and are more likely to have been maltreated in childhood (Granqvist, Forslund, Fransson, Springer, & Lindberg, 2014). Therefore, the current research could have a negative impact if it is read as suggesting parents with ID can parent effectively if their parenting is supported, without appropriate support for these additional contextual and psychological vulnerabilities.

Personal impact.

The research process has also had an impact on me as a developing clinical psychologist. The project has increased my awareness of how ability, and disability, can be constructed by the language we use. I am currently on placement working clinically with marginalised young people who rarely access traditional mental health services, and are used to hearing

stories about their limitations rather than their strengths and capacities. Both the current research and this clinical work has highlighted to me the power of disabling narratives, and has impacted upon my desire to promote competence among marginalised groups. Further, I have become increasingly interested in the role psychologists play working outside of a traditional therapeutic setting, and the results of the research highlights to me the importance of going beyond individual work with parents with ID, and the need to inform policy. To some extent, the research process reflects my development as a clinical psychologist, from an interest in early intervention and family work, to a broader consideration about narratives, community and policy work.

Dissemination

Dissemination of research is an important, and often neglected, part of the research process (Kerner, Rimer, & Emmons, 2005). Sharing results of research with study participants is an ethical imperative (Fernandez, Kodish, & Weijer, 2003) and meaningful dissemination has the potential to increase the reach and impact of research (Penfield et al., 2014). As such, the dissemination strategy is outlined.

The research findings have been disseminated via presentations to staff and students at Royal Holloway University of London. During the presentation, an emphasis was placed on the benefits of incorporating attachment theory into work with people with ID, and the rewarding experience of conducting research around parenting and disability. It is hoped that the presentation spurred the clinical and research interests of qualified and trainee

clinical psychologists. In addition, a summary of the findings of the empirical paper will be sent to all research participants who requested it.

The systematic review will be disseminated to Mind the Gap, a collective of actors with learning disabilities. Mind the Gap have secured funding to develop a training package for health and social care professionals working with parents with ID, and the findings of the systematic review outlining the factors that parents with ID found helpful and unhelpful in support of their parenting holds relevance for this project.

Dissemination through publication allows research to reach a wider audience and facilitates improvements in evidence-based practice. The empirical research will be submitted for publication to notable academic journals which have published similar research. The journals will be approached in the order of preference presented here, which is based on the impact ratings of these journals (SCImgo, 2019). These include the Journal of Intellectual Disability Research, Journal of Applied Research in Intellectual Disabilities, Journal of Intellectual and Developmental Disability and British Journal of Learning Disabilities. The journals were selected based on their scope and acceptance of qualitative research. In addition to journals with a specific focus on ID, generic social work journals will also be approached. The Journal for the Professional Association for Children's Guardians, Family Court Advisers and Independent Social Workers has previously published research exploring the use of VIG. A poster has been accepted for presentation at the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities in August 2019.

The systematic review will also be prepared for publication. Another systematic review being conducted by a trainee clinical psychologist at Royal Holloway University of London is exploring how professionals experience providing support for parents with ID. These two systematic reviews could be combined into a paper for publication.

Academic journals are often inaccessible for people with ID. In order to ensure the accessibility of the research more broadly an accessible summary will be produced. This will be disseminated to self-advocacy groups, and to services who support parents with ID. The Working Together with Parents Network email list will be used to facilitate this.

The empirical paper provided practical applications for the use of VIG with parents with ID, and as such will be disseminated to VIG practitioners. At one of the recruitment sites, two sessions have been organised for me to share the research and the clinical recommendations with VIG guiders who do not currently use VIG with parents with ID, but hope to adopt this approach in the future. Throughout the research process, I made contact with several eminent VIG researchers and practitioners. I will utilise these contacts and offer to disseminate the findings of the empirical paper more broadly to VIG guiders. This will include sharing a summary of findings, the theoretical model generated and a summary of recommendations for VIG guiders working with parents with ID (Appendix 17).

This strategy will allow the research to be consumed by all stakeholders, both professionals and service users, who have the potential to benefit from it.

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Appendices

Appendix 1: Quality ratings using CASP (2018) checklist

	CASP criterion											
	Clear statement of research aims?	Qualitative method appropriate?	Research design appropriate?	Recruitment strategy appropriate?	Data collection appropriate?	Relationship between researcher and participant discussed?	Consideration of ethical issues?	Rigorous data analysis?	Clear statement of findings?	How valuable is the research?	Total score	Category
Included papers												
Llewellyn (1995)	1	1	1	1	1	1	1	1	1	1	10	A
Booth and Booth (1999)	1	0.5	0.5	0.5	0.5	0	0.5	0.5	1	1	6	B
Heinz and Grant (2003)	1	1	1	1	1	0.5	0	0.5	1	0.5	7.5	B
Booth and Booth (2005)	1	1	0.5	1	1	0	0.5	0	1	1	7	B
Tarleton and Ward (2007)	1	1	0.5	1	1	0	0	0.5	1	1	7	B
Tarleton (2008)	1	1	0.5	0.5	1	0	1	1	1	1	8	B
Starke (2010)	1	1	0.5	1	0.5	0.5	1	1	1	1	8.5	A
MacIntyre and	1	1	1	1	1	0	1	0	1	1	8	B

Stewart (2012)													
Tarleton and Porter (2012)	1	0.5	1	0.5	1	0	1	1	1	1	8	B	
Wilson, McKenzie, Quayle and Murray (2013)	1	1	1	1	0.5	0	1	1	1	1	8.5	A	
McGarry, Stenfert Kroese and Cox (2016)	1	1	1	0.5	1	0.5	1	1	1	1	9	A	
Gustavsson and Starke (2017)	1	1	1	0.5	0.5	0.5	0.5	0.5	1	1	7.5	B	
Theodore et al. (2018)	1	1	1	0.5	1	1	1	1	1	1	9.5	A	
Average score	1	0.92	0.81	0.77	0.85	0.31	0.73	0.69	1	0.96	8.04	B	

Appendix 2: Papers contributing to the subthemes of the thematic synthesis

	A negative experience of support			A positive experience of support	
	Experiencing the preconceptions of others	Experiencing the helping relationship negatively	Experiencing elements of support as unhelpful	Experiencing the helping relationship positively	Experiencing elements of support as helpful
Llewellyn (1995)		x	x	x	x
Booth and Booth (1999)		x		x	x
Heinz and Grant (2003)		x		x	x
Booth and Booth (2005)	x	x		x	x
Tarleton and Ward (2007)	x	x	x	x	x
Tarleton (2008)	x	x	x	x	x
Starke (2010)	x	x	x	x	x
MacIntyre and Stewart (2012)		x	x	x	x
Tarleton and Porter (2012)				x	x
Wilson, McKenzie, Quayle and Murray (2013)	x	x	x	x	x
McGarry, Stenfert Kroese and Cox, (2016)	x			x	x
Gustavsson and Starke (2017)				x	x
Theodore et al. (2018)	x	x	x	x	x

Appendix 3: Letter confirming approval from the Health Research Authority



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales



Ms Hannah Alghali
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Research-permissions@wales.nhs.uk

11 July 2018

Dear Ms Alghali

**HRA and Health and Care
Research Wales (HCRW)
Approval Letter**

Study title: Understanding process of change during an attachment based parenting intervention (Video Interaction Guidance; VIG) with parents with intellectual disabilities (ID)

IRAS project ID: 243016

Sponsor: Royal Holloway University of London

I am pleased to confirm that [HRA and Health and Care Research Wales \(HCRW\) Approval](#) has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Following the arranging of capacity and capability, participating NHS organisations should formally confirm their capacity and capability to undertake the study. How this will be confirmed is detailed in the "summary of assessment" section towards the end of this letter.

You should provide, if you have not already done so, detailed instructions to each organisation as to how you will notify them that research activities may commence at site following their confirmation of capacity and capability (e.g. provision by you of a 'green light' email, formal notification following a site initiation visit, activities may commence immediately following confirmation by participating organisation, etc.).

IRAS project ID	243016
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It is important that you involve both the research management function (e.g. R&D office) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details of the research management function for each organisation can be accessed [here](#).

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within the devolved administrations of Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) has been sent to the coordinating centre of each participating nation. You should work with the relevant national coordinating functions to ensure any nation specific checks are complete, and with each site so that they are able to give management permission for the study to begin.

Please see [IRAS Help](#) for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?

HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to [obtain local agreement](#) in accordance with their procedures.

What are my notification responsibilities during the study?

The attached document "*After HRA Approval – guidance for sponsors and investigators*" gives detailed guidance on reporting expectations for studies with HRA and HCRW Approval, including:

- Registration of Research
- Notifying amendments
- Notifying the end of the study

The [HRA website](#) also provides guidance on these topics and is updated in the light of changes in reporting expectations or procedures.

I am a participating NHS organisation in England or Wales. What should I do once I receive this letter?

You should work with the applicant and sponsor to complete any outstanding arrangements so you are able to confirm capacity and capability in line with the information provided in this letter.

The sponsor contact for this application is as follows:

Name: Annette Lock

Tel: 01784414388

Email: annette.lock@rhul.ac.uk

Who should I contact for further information?

Please do not hesitate to contact me for assistance with this application. My contact details are below.

Your IRAS project ID is 243016. Please quote this on all correspondence.

IRAS project ID	243016
-----------------	--------

Yours sincerely

Beverley Mashegede
Assessor

Email: hra.approval@nhs.net

Copy to: Ms Annette Lock, Sponsor Contact

Ms Eirini Tsitsipa, Camden and Islington NHS Foundation Trust, Lead NHS R&D Contact

List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	Version	Date
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance Certificate]		01 August 2017
HRA Schedule of Events	1	26 June 2018
HRA Statement of Activities	1	26 June 2018
Interview schedules or topic guides for participants [Interview Schedule]	1	28 March 2018
IRAS Application Form [IRAS_Form_21052018]		21 May 2018
IRAS Application Form XML file [IRAS_Form_21052018]		21 May 2018
IRAS Checklist XML [Checklist_21052018]		21 May 2018
Non-validated questionnaire [Demographics Questionnaire]	1	28 May 2018
Non-validated questionnaire [Screening Questionnaire]	1	31 December 2017
Other [Proposal Comments from Reviewers]	1	31 December 2017
Other [Proposal Approval]	1	27 February 2018
Participant consent form	2	10 July 2018
Participant information sheet (PIS)	2	10 July 2018
Research protocol or project proposal [Proposal version 2]	2	31 December 2017
Summary CV for Chief Investigator (CI) [CI CV]		02 May 2018
Summary CV for student [CI CV]		02 May 2018
Summary CV for supervisor (student research) [Academic Supervisor CV]		02 May 2018
Summary CV for supervisor (student research) [Academic Supervisor CV]		02 May 2018

Summary of assessment

The following information provides assurance to you, the sponsor and the NHS in England and Wales that the study, as assessed for HRA and HCRW Approval, is compliant with relevant standards. It also provides information and clarification, where appropriate, to participating NHS organisations in England and Wales to assist in assessing, arranging and confirming capacity and capability.

Assessment criteria

Section	Assessment Criteria	Compliant with Standards	Comments
1.1	IRAS application completed correctly	Yes	No comments
2.1	Participant information/consent documents and consent process	Yes	No comments
3.1	Protocol assessment	Yes	No comments
4.1	Allocation of responsibilities and rights are agreed and documented	Yes	The Sponsor intends to use the Statement of Activities as the form of agreement with participating organisations.
4.2	Insurance/indemnity arrangements assessed	Yes	Valid insurance certificate.
4.3	Financial arrangements assessed	Yes	No application for external funding made.
5.1	Compliance with the Data Protection Act and data security issues assessed	Yes	No comments
5.2	CTIMPS – Arrangements for compliance with the Clinical Trials Regulations assessed	Not Applicable	No comments
5.3	Compliance with any applicable laws or regulations	Yes	No comments
6.1	NHS Research Ethics Committee favourable opinion	Not Applicable	This study does not need REC review.

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Section	Assessment Criteria	Compliant with Standards	Comments
	received for applicable studies		
6.2	CTIMPS – Clinical Trials Authorisation (CTA) letter received	Not Applicable	No comments
6.3	Devices – MHRA notice of no objection received	Not Applicable	No comments
6.4	Other regulatory approvals and authorisations received	Not Applicable	No comments

Participating NHS Organisations in England and Wales

<i>This provides detail on the types of participating NHS organisations in the study and a statement as to whether the activities at all organisations are the same or different.</i>
<p>This is a non-commercial student (Doctorate in Clinical Psychology) study and there is one site type.</p> <p>The Chief Investigator or sponsor should share relevant study documents with participating NHS organisations in England and Wales in order to put arrangements in place to deliver the study. The documents should be sent to both the local study team, where applicable, and the office providing the research management function at the participating organisation. Where applicable, the local LCRN contact should also be copied into this correspondence.</p> <p>If chief investigators, sponsors or principal investigators are asked to complete site level forms for participating NHS organisations in England and Wales which are not provided in IRAS, the HRA or HCRW websites, the chief investigator, sponsor or principal investigator should notify the HRA immediately at hra.approval@nhs.net or HCRW at Research-permissions@wales.nhs.uk. We will work with these organisations to achieve a consistent approach to information provision.</p>

Principal Investigator Suitability

<i>This confirms whether the sponsor position on whether a PI, LC or neither should be in place is correct for each type of participating NHS organisation in England and Wales, and the minimum expectations for education, training and experience that PIs should meet (where applicable).</i>
<p>A Local Collaborator is expected at each participating organisation.</p> <p>GCP training is <u>not</u> a generic training expectation, in line with the HRA/HCRW/MHRA statement on training expectations.</p>

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HR Good Practice Resource Pack Expectations

This confirms the HR Good Practice Resource Pack expectations for the study and the pre-engagement checks that should and should not be undertaken

No access arrangements are expected for staff only studies undertaken in non-clinical areas.

Other Information to Aid Study Set-up

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales to aid study set-up.

The applicant has indicated that they do not intend to apply for inclusion on the NIHR CRN Portfolio.

Appendix 4: RHUL ethics approval



Ethics Review Details

You have chosen to self certify your project.	
Name:	Alghali, Hannah (2016)
Email:	NDJT001@liva.rhul.ac.uk
Title of research project or grant:	Process of change: Video Interaction Guidance with parents with ID
Project type:	Royal Holloway postgraduate research project/grant
Department:	Psychology
Academic supervisor:	Kate Theodore
Email address of Academic Supervisor:	Kate.Theodore@rhul.ac.uk
Funding Body Category:	No external funder
Funding Body:	
Start date:	30/07/2018
End date:	30/07/2019

Research question summary:

Parents with intellectual disabilities (ID) face multiple challenges to their parenting and a presumption of parenting incompetence. However, many parents benefit from evidence-based training programmes and with the right support are able to raise children effectively.

In the UK, attachment-based interventions such as Video Interaction Guidance (VIG), are increasingly being used to support positive parenting and have been found to enhance parenting sensitivity and increase attachment security. Qualitative research has explored the experiences of parents and VIG practitioners to highlight the impact of the intervention and mechanisms that facilitate change.

However, despite VIG being offered to parents with ID, little is known about how VIG facilitates change for parents with ID specifically. Some initial research has explored outcomes of VIG when working with parents with ID, as well as their perspectives on processes of change. Therefore, the current study aims to extend this by exploring, from the perspective of VIG guiders, the impact of VIG for parents with ID and what facilitates or hinders change during VIG. Grounded theory will be used to develop a model of the processes which facilitate change. It is hoped this will improve the application of VIG and promote positive parenting among this group.

Therefore, my research questions are:

What are the outcomes and impact of Video Interaction Guidance (VIG) with parents with intellectual disabilities (ID), from the perspective of VIG guiders?

What do VIG guiders' perceive to be the factors that facilitate (or hinder) change during a VIG intervention with parents with ID?

Research method summary:

VIG guiders will be interviewed using an interview schedule.

Risks to participants

Does your research involve any of the below?

Children (under the age of 16),

No

Participants with cognitive or physical impairment that may render them unable to give informed consent,

No

Participants who may be vulnerable for personal, emotional, psychological or other reasons,

No

Participants who may become vulnerable as a result of the conduct of the study (e.g. because it raises sensitive issues) or as a result of

Is there a risk that any of the material, data, or outcomes to be used in this study has been derived from ethically-unsound procedures?,
No

Details,

These issues have been address and approved by NHS ethical approval.

Risks to the Environment / Society

Will the conduct of the research pose risks to the environment, site, society, or artifacts?,
No

Will the research be undertaken on private or government property without permission?,
No

Will geological or sedimentological samples be removed without permission?,
No

Will cultural or archaeological artifacts be removed without permission?,
No

Details,

Risks to Researchers/Institution

Does your research present any of the following risks to researchers or to the institution?

Is there a possibility that the researcher could be placed in a vulnerable situation either emotionally or physically (e.g. by being alone with vulnerable, or potentially aggressive participants, by entering an unsafe environment, or by working in countries in which there is unrest)?,
No

Is the topic of the research sensitive or controversial such that the researcher could be ethically or legally compromised (e.g. as a result of disclosures made during the research)?,
No

Will the research involve the investigation or observation of illegal practices, or the participation in illegal practices?,
No

Could any aspects of the research mean that the University has failed in its duty to care for researchers, participants, or the environment / society?,
No

Is there any reputational risk concerning the source of your funding?,
No

Is there any other ethical issue that may arise during the conduct of this study that could bring the institution into disrepute?,
No

what is revealed in the study (e.g. criminal behaviour, or behaviour which is culturally or socially questionable),

No

Participants in unequal power relations (e.g. groups that you teach or work with, in which participants may feel coerced or unable to withdraw),

No

Participants who are likely to suffer negative consequences if identified (e.g. professional censure, exposure to stigma or abuse, damage to professional or social standing),

No

Details,

Design and Data

Does your study include any of the following?

Will it be necessary for participants to take part in the study without their knowledge and/or informed consent at the time?,

No

Is there a risk that participants may be or become identifiable?,

Yes

Is pain or discomfort likely to result from the study?,

No

Could the study induce psychological stress or anxiety, or cause harm or negative consequences beyond the risks encountered in normal life?,

No

Does this research require approval from the NHS?,

Yes

If so what is the NHS Approval number,

243016

Are drugs, placebos or other substances to be administered to the study participants, or will the study involve invasive, intrusive or potentially harmful procedures of any kind?,

No

Will human tissue including blood, saliva, urine, faeces, sperm or eggs be collected or used in the project?,

No

Will the research involve the use of administrative or secure data that requires permission from the appropriate authorities before use?,

No

Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?,

No

Details,

Declaration

By submitting this form, I declare that the questions above have been answered truthfully and to the best of my knowledge and belief, and that I take full responsibility for these responses. I undertake to observe ethical principles throughout the research project and to report any changes that affect the ethics of the project to the University Research Ethics Committee for review.

Certificate produced for user ID, NDJT001

Date:	12/07/2018 13:07
Signed by:	Alghail, Hannah (2016)
Digital Signature:	Hannah Alghail
Certificate dated:	7/12/2018 1:51:11 PM
Files uploaded:	243016 Participant Consent Form version 2.doc 243016 Participant Information Sheet version 2.docx

Appendix 5: Interview schedule

Process of change: VIG with parents with ID
IRAS ID: 243016
Version 1
Date: 28/3/18



Interview Schedule for VIG Guiders

Introduction

- Thank you very much for coming to speak to me today.
- Do you have any questions about anything at all on the information sheet?
- How are you feeling about talking to me today?
- Is there anything I can do to make it feel more comfortable?
- If you want to stop the interview at any time, please let me know.
- If you want to take a break for any reason at any point, please let me know and we can do that.

Confidentiality

As explained in the information sheet, everything that we discuss today will be treated confidentially. The only reason I would need to involve anyone else in our discussion today or share what we discussed would be if I had concerns that you, or someone else were at risk of harm. If that did happen, I would discuss it with you before talking to anyone else. Do you have any questions?

Interview themes

Guider's experience

- What are your experiences of using VIG with parents who have or are considered to have learning disabilities / difficulties (LD)?

Impact of VIG

- What changes have you noticed following a VIG intervention with parents with LD?
- What do you think are the most important outcomes for parents with LD following VIG?
- If you have also used VIG with parents without LD, have you noticed any differences in outcomes when working with parents with LD?

Prompt for examples of above if appropriate i.e. Can you give me an example of that in practice?

Methodological components of VIG

- Are there any parts of the VIG protocol you found worked particularly well with parents with learning disabilities?

Prompt: Can you give me an example of how that has worked in practice?

- Are there any parts of the VIG protocol that you found difficult when working with parents with learning disabilities? If yes, how did you overcome this difficulty?

Prompt: Can you give me an example of how that has worked in practice?

- How, if at all, do you adapt your delivery of VIG when working with parents with learning disabilities?

Prompt: Can you give me an example of that in practice?

- Is there anything you would do differently in the future when using VIG with parents with learning disabilities?

Prompt: How do you think this would enhance the effectiveness of VIG when working with parents with LD?

Underlying mechanisms of change

- Over the course of the VIG, what changes did you notice for the parent with LD and their family?
- Did you notice a change in how the parent talked about themselves as a parent?
- Did you notice a change in how the parent talked about their child?
- Did you notice a change in how the parent talked about their interactions with their child?
- If yes, how do you think this facilitated behavioural change, if at all?

Prompts to questions above: What did you notice? Can you give an example?

- In your opinion, what underlying factors contribute to change for parents with learning disabilities?
- How would you describe the therapeutic relationship when working with parents with LD during VIG?

Prompts: Did you notice any changes in therapeutic relationship over the course of the VIG intervention? If so, what did you notice? Can you give an example of that in practice?

- How, if at all, do you think the therapeutic relationship impacts upon VIG with parents with LD?

Contextual and individual factors

- Did any of the parents with LD you worked with find VIG particularly difficult to engage with?

Prompt: why do you think that was?

Prompt: Individual factors, environmental factors, therapeutic / other relationship factors, factors related to the professional?

Impact on clinician

- Have you noticed that working with parents with LD has impacted upon your VIG interventions more broadly? If so, how?

Debrief

- Is there anything that we have not covered that you think is important or that you would like to tell me about?
- Do you have any questions about anything that we have talked about or the study in general?
- Explain what will happen next – I will be talking to a number of other people and asking them similar questions. I will listen to each interview and transcribe them. After I've done that, each recording will be deleted. The transcribed file will not have your name on it. I will analyse all of the written interviews, looking for themes and links. Then I will write them up into a thesis for submission.
- Would you like more information about what I have found when I have it?
- Would you be interested in giving me some feedback on the findings / model?

Appendix 6: Extracts from the reflective log

After second interview

I finished my second interview today. I think lots of interesting ideas are emerging, and there already seems to be lots of differences from Doria et al.'s (2014) model. I think it would be good to explore a bit more about the contextual factors which impact on the intervention.

I'm thinking back to before I started the research, before I knew much about the area. I was focusing on parenting limitations and ways to support these. Then I read about how context impacts on parents with ID / IQ and parenting ability are not causally related. Anyway, I want to explore a bit more about context in the next interviews, and not be too focused on parents' limitations because of ID. Need to be more mindful of timing, context questions come at the end. Also reminder to keep contextual factors in mind as they emerge throughout the interview.

After fourth interview

Reflected on the need to spend less time focusing on outcomes with clients, and think more about mechanisms of change. Hoping this will make the research 'richer'.

Initial coding first interview

I notice myself being interested in power and social construction / restraints around the intervention. I notice myself wanting to jump to thematic interpretations, but remembering to stay close to the data. Starting to notice a theme of 'a different experience'.

Initial coding fifth interview

Having an idea about the power of the image and the fact it cannot be argued with. There is power in not being able to dispute the fact. Guider elicits emotions seems important, and then translate the emotional response into action. Also emotions of the guider, lots of guiders spoke with passion.

Initial coding seventh interview

Trying not to think / assume the most experienced guider has all the answers. As Mays and Pope (2000) said, shouldn't let one voice speak for all. Noticing in myself a desire to find out if ID or the context has most of the impact, mindful not to impose this idea on to the data

Processes to reviewing initial codes with second reviewer

Noticed that I had mainly been focusing on the parents' experience, and not acknowledging the guiders' experience. Noticed myself making some theoretical leaps, and could have stayed closer to the data. Also noticed sometimes I missed codes when they had been said earlier. Reminded me of the importance of coding each line. To do – review the codes I have already done, write down these as reminders for future coding.

e.g. I said 'limitations with insight', second reviewer said "Guider thinking it was difficult for dad to say things were difficult at start because social services involved"

After focus coding on 3rd interview

Noticed the value in line by line coding and focus coding. The themes I thought were emerging the strongest during the interviews turn out not necessarily to be. E.G. I thought there was loads about trauma vs LD and insight. Line by line coding helped the themes to emerge from the data.

Appendix 7: Participant information sheet

Process of change: VIG with parents with ID
IRAS ID: 243016
Version 2
Date: 10/7/18



Participant Information Sheet

Study title

Understanding process of change during Video Interaction Guidance (VIG) with parents with learning disabilities (LD).

Invitation and brief summary

We'd like to invite you to take part in our research study. Joining the study is entirely up to you, before you decide we would like you to understand why the research is being done and what it would involve for you. Please feel free to ask the researcher any additional questions you may have. Please feel free to talk to others about the study if you wish.

This study aims to explore the use of Video Interaction Guidance (VIG) with parents with learning disabilities (LD) in the hope of understanding the factors that facilitate, or hinder, change during the VIG intervention with this client group. We are looking for VIG guiders who have worked with parent(s) with LD to take part. Taking part in this study will involve an interview lasting up to 60 minutes. The interviews will be transcribed and the researchers will write a report, based on the information collected. The interviews will take place either at your place of work or over Skype.

Purpose and background to the research

Parents with LD face multiple challenges to their parenting. However, many parents benefit from evidence-based training programmes and with the right support are able to raise children effectively.

In the UK, attachment-based interventions such as Video Interaction Guidance (VIG), are increasingly being used to support positive parenting and have been found to enhance parenting sensitivity and increase attachment security. Research has explored the experiences of parents and VIG practitioners to highlight the impact of the intervention and mechanisms that facilitate change.

However, despite VIG being offered to parents with LD, little is known about how VIG facilitates change for parents with LD specifically. Some initial research has explored outcomes of VIG when working with parents with LD, as well as their perspectives on processes of change. The current study aims to extend this by exploring, from the perspective of VIG guiders, the impact of VIG for parents with LD and what facilitates or hinders change during VIG. It is hoped this research will improve the application of VIG and promote positive parenting among this group.

We are hoping to recruit and interview between six and ten VIG guiders who have worked using VIG with parent(s) with LD in order to understand the factors which impact upon change, and we would like to invite you to take part.

This research is being undertaken as part of the research requirements for a doctorate in clinical psychology at Royal Holloway University of London.

What would taking part involve?

If you agree to take part, you will be interviewed by a researcher for up to 60 minutes. You will be asked some brief, anonymous information about you and your professional role. The interview will focus on your experience of using VIG with parents with LD. The interview will take place either at your work place or over Skype, at a time that is suitable for you. The interviews will be audio recorded and transcribed by the researcher. The final report may include direct quotations from you, but the report will not include any information which will make it possible to identify you. In order to ensure the anonymity of the parents who you have worked with, you will be asked not to share any identifying information about them. If this information is shared, it will not be included in the final report.

The recorded interviews will be kept on an encrypted memory key and will be deleted once they have been transcribed. The interview transcripts will be kept anonymously and securely, and will not include any identifiable information. The transcripts will only be accessed by the research team, for the purposes of research.

You will be reimbursed for your travel to and from the interview location if this is additional to your travel for your work.

How have service users been involved in the study?

NHS staff were involved in reviewing the Participant Information Sheet.

As participants, you will also be invited to give feedback on the findings of the research interviews, if you wish to do so.

The researchers plan to seek support from people with LD to develop an accessible summary of the research, to ensure that research can be accessed and understood by people with LD.

What are the possible benefits of taking part?

You may find it interesting to reflect on your clinical work. The research is also likely to benefit parents with LD who receive a VIG intervention in the future, as the intervention may be tailored based on the results of the research.

What are the possible disadvantages and risks of taking part?

It is not predicted that the research will involve significant risks for you. However, the research will take up some of your time. We do not expect the interview to be too sensitive or distressing for you; however you are free not to answer any of the questions. If you find anything distressing, we can talk about what support you may find helpful after the interview. If, at any time, safeguarding concerns are raised regarding a child or a vulnerable adult, the researcher will discuss these concerns with the service lead. We will let you know first if we need to do this.

There is a small chance of identifiable information accidentally being disclosed. In order to reduce this risk, pseudonyms will be given to each participant. Interviews will be transcribed as soon as possible after the interview, and any identifiable information removed from the transcripts; audio recordings will be deleted as soon as interviews are transcribed. Additionally, signed consent forms will be kept securely and separately from interview transcripts.

What will happen if I don't want to carry on with the study?

You can change your mind and decide not to take part in the study at any point until we have completed the study. In this instance, any information that had your personal details on it will be destroyed.

What if there is a problem?

If you have a concern about this study, you should speak to Dr Kate Theodore (lecturer at Royal Holloway University of London and research supervisor) on 01784 414 303 who will do her best to answer your questions.

How will my information be kept confidential?

Your information will be stored securely. Your interview answers will be stored without your name on them. Audio recordings will be deleted as soon as the interview has been transcribed. Your consent form will be kept for 2 years, and your interview answers will be kept for 5 years then destroyed. We will not use these for future studies. Only the researchers and people who inspect researchers will have access to your data.

How is this research being conducted in line with the new General Data Protection Regulation (GDPR) guidance?

Royal Holloway University of London is the sponsor for this study based in England. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. Royal Holloway University of London will keep identifiable information about you for 5 years after the study has finished, for auditing purposes.

Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally-identifiable information possible.

Your employing NHS site will use your name, and contact details to contact you about the research study, and make sure that relevant information about the study is recorded to oversee the quality of the study. Individuals from Royal Holloway University of London and regulatory organisations may look at research records to check the accuracy of the research study. Your employing NHS site will pass these details to Royal Holloway University of London along with the information collected from you. The only people at Royal Holloway University of London who will have access to information that identifies you will be people who need to contact you to audit the data collection process. The people who analyse the information will not be able to identify you and will not be able to find out your name, or contact details.

You can find out more about how we use your information by at <https://www.nhs.uk/your-nhs-data-matters/who-uses-your-data/> or by contacting Dr Kate Theodore (lecturer at Royal Holloway University of London and research supervisor) on 01784 414 303 who will do her best to answer your questions.

Who is organising and funding the research?

Royal Holloway, University of London, as part of the Doctorate in Clinical Psychology.

Who has reviewed the study?

The study has been reviewed by the Royal Holloway ethics committee, and has received research and development approval from the NHS.

If you are interested in taking part in the study, please contact the research on the contact details below to discuss the research in more detail. If you decide to take part, you will be given a copy of this information sheet and a signed consent form to keep.

Hannah Alghali
Trainee clinical psychologist and researcher
hannah.alghali.2016@live.rhul.ac.uk

Dr Kate Theodore
Lecturer at Royal Holloway University of London and research supervisor
kate.theodore@rhul.ac.uk

Oliver Schuman
Lecturer at Royal Holloway University of London and research supervisor
oliver.schauman@rhul.ac.uk

Appendix 8: Participant consent form

Process of change: VIG with parents with ID
IRAS ID: 243016
Version 2
Date: 10/7/18



Consent Form

Title of Project: Understanding process of change during an attachment based parenting intervention (Video Interaction Guidance; VIG) with parents with intellectual disabilities (ID)
Name of Researcher: Hannah Alghali

Please initial box

1. I confirm that I have read the information sheet dated 10/7/18 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care, professional role or legal rights being affected.
3. I consent to the use of audio-recording, with the possible use of verbatim quotation.
4. I understand that confidentiality and anonymity will be maintained and it will not be possible to identify me in any publications.
5. I agree to take part in the above study.

Name of Participant Date Signature

Name of Person Date Signature
taking consent

Appendix 9: Demographics questionnaire

Process of change: VIG with parents with ID

IRAS ID: 243016

Version 1

Date: 28/3/18



Demographics Questionnaire

To begin, I'd like to get some information about yourself and your professional role. This will help readers of my research to assess its relevance. The information you provide will never be used to identify you as my research will be reported anonymously. However, if you don't want to answer some of these questions, please don't feel that you have to.

1. Are you

(tick the appropriate answer)

Male

Female

2. How old are you? [] years

3. How would you describe your ethnicity?

4. What is your professional background? E.g. Clinical psychologist, social worker etc.

5. In what year did you begin your VIG training?

6. Was this training accredited by AVIGuk? YES NO

7. What level of VIG training have you completed?

8. At what service(s) do/have you worked using VIG?

9. How many parents with learning disabilities have you worked with using VIG?

10. If you do not work in a service for people with learning disabilities, can you tell me a little bit about how the learning disability was established?

11. What are the timescales of this work?

Appendix 10: Credibility checks – feedback on the model from participants

Thank you for agreeing to review my model. This will provide credibility checks for my research, and I will edit the model based on the feedback I receive. I have included a narrative description and a diagram of the model.

It would be great if you could have a look over the model and let me know your thoughts on the following points.

- Does the model fit with your experience of using VIG with parent(s) with learning disabilities?
- Are there any parts of the model which deviate from your experience of using VIG with parent(s) with learning disabilities?
- Are there any parts of your experience using VIG with parent(s) with learning disabilities which are not captured in the model?
- Did the development of a new narrative feel like an important part of your work?

A model of the impact of VIG with parents with intellectual disabilities (ID) and the factors which facilitate and hinder change

The study aimed to generate a theoretical model to explain the process of change during VIG with parents with ID. The resulting model, based on participants' accounts, is a diagrammatical representation of the impact of VIG and the factors which facilitated and hindered change. Arrows demonstrate direction of influence.

Before VIG began, parents with ID had a broadly negative view of parenting and their child. Their confidence in their parenting ability was low and their parenting skills limited. They held negative expectations for the relationship with the VIG guider, their own ability to engage and were concerned about being filmed. These factors contributed to difficulties with engagement with VIG, and the guiders worked to allay some of these concerns in order to promote a successful intervention.

Once a parent engaged with VIG, the process of change began. Parents saw themselves interacting successfully and differently on video. This experience was associated with an emotional response. Parents experienced positive emotions which was reinforcing, leading them to repeat the behaviour. Parents also experienced negative emotions which also encouraged the desired behaviour to be repeated, perhaps due to cognitive dissonance. Sharing successes with others was also reinforcing and again encouraged the behaviour to be repeated. Parents began to feel more confidence in their parenting ability, and thus there are more opportunities for positive filmed interactions. The focus on positive

parenting and increasing confidence contributed to the development of a new narrative. Parents began to see themselves, their child, and the relationship more positively. As a result, the parents are more able to see the successes in the filmed interaction, leading to a positive experience of the second shared review. This change occurred in the context of a therapeutic relationship which allowed the guider to model parenting skills and empower parents.

The change process contributed to improvement in child development, the parent child relationship, parenting skills, and the parents' relationship with the systems. These outcomes fed back into the process of change: as parenting improves, so does the opportunity for successful filmed interactions. These outcomes are hindered by both parent and guider intrapersonal factors, as well as interpersonal and contextual factors. The outcomes can be facilitated by adapting the VIG protocol for parent's learning needs and providing mental health support for parents. Guider's own supervision, a focus on engagement and the social care context can also facilitate the outcomes of the intervention.

Summary of feedback from participants:

In order to provide credibility checks, feedback from participants was sought (Mays & Pope, 2000). In general, the five guiders who provided feedback felt the model fitted with their experience, and a new narrative was felt to be a significant contributor to change. The feedback emphasised that while the model provided a good summary of their experience, there were individual differences. For example, not all parents were difficult to engage. Similarly, the feedback highlighted many parents without ID who receive VIG have vulnerabilities, for example mental health needs, having been in care, or environmental adversity. These factors may account for the similarities found between parents with and without ID in the literature.

The participant feedback highlighted the importance of attunement between parent and guider, which is often a new experience for parents with ID. Attunement was highlighted in the results, but neglected from the model and discussion. As such, this was made more explicit in the final model.

Appendix 11: Example of the initial coding process

Initial codes	Extract on interview transcript from participant 1
	<p>Researcher: My first question is um if you could just tell me a little bit about how you generally experience conducting VIG with parents with learning disabilities?</p>
<p>VIG guider enjoying VIG Seeing something Parents connecting to film</p> <p>Given stills of film</p> <p>Holding stills of film</p> <p>Owning stills of film, giving parents ownership of the intervention</p> <p>Parents having control Parents making the intervention helpful Giving space and time Adapting explanations of the intervention, using cartoons Difficulty understanding language e.g. initiatives</p>	<p>Participant: Oh really well firstly just an absolute delight to do because it it just, you're offering the opportunity for them to see something and and visual um it's just a way that the parents just make such big connections. So um one of my mums I actually sort of took a screen shot of the still and then printed it both in colour and black and white, and then laminated it. So I could physically sort of give that to her so that she could actually sort of hold that. And and you know move it wherever she wanted to so she could see it better which meant I feel it just gives people much more ownership, much more control over what they need to do to look at it in a way that's going to be helpful to them. And just giving a lot more time and space ... um and ...I use the cartoons, the AVIG cartoons to explain the background because they really like that. Although I do think with AVIG some of the language sometimes like 'initiatives'... the parents that I work with didn't understand.</p>
	<p>R: I see, so it's a bit complicated, some of the language.</p>
<p>Explaining simply Using simple language Using parents' language in shared reviews Connecting through shared language</p>	<p>P: The language so I would just explain just keep things just really simple and just use much more language that they would be able to access and understand and very much using their language within the shared reviews. That I can connect with them and then we could connect together.</p>
<p>Sharing language Sharing understanding</p>	<p>R: Yeah, so being on the same sort of, a shared language and a shared understanding of the intervention and difficulties as well it sounds like.</p>
	<p>P: Yeah.</p>
	<p>R: Ok and um what sort of changes or outcomes have you noticed following VIG interventions with parents with learning disabilities?</p>
<p>Starting superficially, at a basic level</p> <p>Starting at a parents' level of understanding Parents bringing their own understanding Wanting to that he can hold his baby ok</p>	<p>P: So the helping questions are quite interesting umm because I think they start off with something quite sort of maybe on a more superficial very basic sort of level and um I think that's really important because that's their that's what they're bringin of their way of understanding. So one dad that I worked with a diagnosed learning disability said um he didn't, he just wanted to see that he was holding the baby... ok. And</p>

<p>Coming back to parents starting point Parent being uncertain of basic skills Guiders taken holding baby for granted Starting where they are, what they're worried about Introducing being attentive</p> <p>Introducing reciprocal communication Starting in an easier way for someone to access</p>	<p>you know, when we think about VIG and attachment and you know the more complexity of what we're looking at, I actually had to come back to the point where he was at. He was nowhere near there. He literally just wasn't sure if he was <i>holding</i> his baby ok. And if we think about that's such a fundamental basic of what we would assume is just you know a basic thing, taken for granted that people do so I think it's really starting at where they, what they were worried about and then from there we were able to just look at maybe the baby's face when he you know, or his face, and some very little things so you're helping to introduce the concept of being attentive um and that the communication the reciprocal communication starting but in a much more um sort of easier to, I don't know how to explain myself, but in an easier way for someone to access.</p>
<p>Starting behaviourally</p>	<p>R: It sounds like sort of starting quite behaviourally before thinking more about the yeah attachment theory and the relationship and the connection between parent and child?</p>
	<p>P: Yes.</p>
	<p>R: And I think quite often parenting interventions of parents with learning disabilities tend to focus on quite behavioural, this is how you change a nappy, this is how you warm up milk. Um but I think from what you're saying, the VIG can go above and beyond that?</p>
	<p>P: Yes</p>
	<p>R: But to start in that way.</p>
<p>Starting gently Introducing different ideas, how the baby might feel</p> <p>Seeing the impact on the child, it feel safe Thinking about how the child is feeling Making links to child's internal world</p>	<p>P: But to start with the you know, to start there but then very gently um maybe think about a different idea of maybe how the child's looking, or how the child might be feeling when he was holding him in a really nice way. You know he could see that he was you know keeping the baby safe and then from building how the child feels, it feels safe. "How do you feel?" "I feel safe". So you kind of then are able to very gently very small sort of steps to make links but but starting yeah.</p>
	<p>R: And how did you find that? That I guess it's quite a complex cognitive ability to understand how someone else is thinking. How did you find that was in the intervention. Was that ok?</p>
<p>Starting with what the parent is seeing Moving on to what the child is feeling Parent limited in language and cognition Parent linking child's smile to emotions and feelings</p>	<p>P: So it was we could only do the feelings once we had established what we could see. So once he could see that the baby was happy and smiling, you know, then we were able to think you know how he was feeling. He used very very, it was very limited in the sort of cognition and the language. So he could see a smile, then he could link to that being happy and maybe that feel nice.</p>

<p>Reflecting on parent's role Linking to helping questions Interlinking what could be seen with what child might feel to increase understanding Helping parent's confidence</p>	<p>R: Yeah. And it's clear the value of having the video and the stills to otherwise perhaps you wouldn't have been able to breach that and move further on. So um yeah ok.</p>
<p>Seeing responding to baby on film Seeing the baby's communication, using video</p>	<p>P: And then you could we could sort of think you know, did he think he was doing a good job. We could link that to the helping question – am I holding the baby – and it just had to stay very um sort of like you know very interlinking things that you could sort of think, happy, smile, happy um nice and then just sort of thinking what he was doing and it basically it just helped his confidence. That's where it moved forward um and then we the second time, the second cycle, we noticed I filmed and the baby was you know they fidget a bit? The baby was sort of getting a bit restless and he he moved the baby into a different position, a bit higher up I think, and held him then and then we were able to look at that little bit of video and think that he could then see that he he was able to sort of move him on and the baby was trying to tell him something “how did you know the baby, how did you know” and he could see that he moved the baby but you know “why”. And he said “oh cos he made that wriggle” “and that great, so he wriggled and you moved.” He watched it and watched it as many times you know probably you know even more than I might with someone else because there might be more discussion and interpretation of the clip but with someone you really are just “let's look and see”.</p>
<p>Reflecting with parent on their role, why did you do that? Parent interpreting baby's wriggle</p>	
<p>Watching the video repeatedly Less discussing and interpreting, more looking and seeing</p>	

Appendix 12: Developing focused codes

First draft of focused code	Examples of initial codes and participant number
How parents come into the intervention / their goals and expectations for the intervention	Parting nervous to start and to be filmed (P2) Parent being uncertain of basic skills (P1) Being different because of LD (P1) Feeling different when interacting with services (P1) Being matter of fact about losing children (P1) Parent worrying about parenting skills (P1) Parents wanting to try (P1) Parents worrying if they're doing it right (P9) Guarded at begging (P9) Masking at the beginning, wanting to say the right thing (P9) Parent feeling uncomfortable with first meeting (P9) Dad saying he wouldn't find filming strange (P3) Dad initially saying he wanted more contact (P3) Parent wanting to prove they are a good parent (P4) Parent being concerned about getting it wrong (P3) Wanting more time with child (P3) Parent being unsure of guiders expectations (P4) Experiencing professionals as untrustworthy (P4) Being terrified of saying something wrong (P4) Parents feeling scared of the review, uncertainty (P4) Wanting to be the good mum that her children deserve (P5) Parent feeling unable to do VIG (P6) Parents wanting to feel more confident (P6) Parents wanting to help daughter to feel/be safe (P6) Initially parent has narrow focus/reflective capacity (P8) At the beginning, didn't think children liked her (P8)
Impact of context / power on parenting and VIG	Accepting how it is (P1) Resigning to how it is (P1) Power of services impacting parents (P1) Having a passive approach (in the face of services) (P1) Feeling powerless (P1) Parents learning they cannot challenge systems (P1) Guiders awareness of parents limitations in social care context (P1) Parents feeling scared of children being taken away (P1) Guider initially thinking contact was soul destroying because someone just making notes about dad (P3) Punitive/controlling view of parenting with LD (P3) Society's assumptions parents with LD are bad (P3) Context of scrutinizing (P4) Context of difficulties and errors being highlighted (P4) Parents make few initiatives (P4) Negative social responses to LD, limiting initiatives (P4) Social learning impacting on initiatives (P4) Parents experience being shamed for their initiatives (P4) Waiting for initiatives can reinforce power (P4) Parents not understanding systems (P6)

Parents seeing exceptions / something they didn't think was the case

Showing images different to parents ideas (P6)
Showing co-smiling (which is different to what mum thought happened) (P6)
Emotional impact of visuals (different way of experiencing parenting) (P6)
Asking parent about exceptions (P6)
Reflecting on what had been different to other times (P6)
Noticing things they hadn't noticed before (P7)
Seeing themselves doing something different, increases confidence (P7)
Watching, experiencing the difference (P7)
Parents sad emotional response to seeing the exceptions (P7)
Showing parents best bits, parents realising it can't be maintained, parents reflecting on the need to not have children again soon (P7)
VIG revealing that there was love (P8)
Parent seeing love (P8)
Seeing something new (P8)

Parent thinking about self differently

Reflecting on parent's role (P1)
Reflecting on the interaction, altering perceptions of self (P1)
Changing perception of self (P1)
Encouraging parent to get a new perspective (P1)
New sense of self (P9)
I did this, acknowledging role (P3)
Increased self-efficacy leading to change (P4)
Parent's recognising own role in play (P4)
Seeing something different in themselves (P5)
Looking at themselves in a different way (seeing in the literal sense, but also in a narrative sense) (P5)
Parent noticing their emotional response to their child (P5)
Parent seeing themselves as more competent (P6)
Parent seeing role in communication (I6)
Parent having more self-awareness (P8)

LD as a limiting factor to protocol

Introducing attachment language can be a struggle for parents (P9)
Dad taking time to understand intervention (P3)
Difficulty expressing abstract concepts effecting the shared review (P4)
Going beyond seeing was difficult (due to abstract) (P4)
Limiting metacognitive Conversations (P4)
Change not achieved through meta cognitions (P4)
Parents saying less in shared reviews (P5)
Difficulty remembering previous sessions (P5)
Difficulty mentalizing linked to LD (P6)
Parents difficulty understanding child development (P6)
Parents giving yes/no answers (P6)
Emotional / cognitive learning needing more time to be embedded (P6)
IQ impacts on parent's ability to hold several things in mind (P7)
Tangential talking, hard to focus on task (P8)

Appendix 13: Developing theoretical and focused codes

Theoretical code	Focused code	Examples of initial codes and participant number
Parents and parenting before VIG	Negative expectations	<p>Parent expecting to be told what they're doing wrong (P2)</p> <p>Parent assumption of criticism (P4)</p> <p>Parent's expectation of being shut down (P4)</p> <p>Parent thinking VIG is waste of time (P6)</p> <p>Parents feeling scared of the review, uncertainty (P4)</p> <p>Parent feeling unable to do VIG (P6)</p> <p>Parents unhappy with other interventions (IP5)</p>
	Concerns about filming	<p>Why?</p> <p>Scrutiny from services creating concerns about videoing (P4)</p> <p>Initially being suspicious of being filmed, concern about who will see video (P5)</p> <p>Parents worrying video will be used negatively (P8)</p> <p>Concern</p> <p>Parting nervous to start and to be filmed (P3)</p> <p>Filming feeling intrusive (P9)</p> <p>Filming intimidating (P9)</p> <p>Resistant to filming (P9)</p> <p>Camera feeling threatening, parents feeling scrutinised (P8)</p> <p>Parents worrying about being filmed (P8)</p> <p>Scared about being filmed (P8)</p> <p>Managing</p> <p>Helping parents understand video will be used positively (P8)</p> <p>Guider keeping camera discreet (P8)</p> <p>Encouraging during first filming (P9)</p> <p>Being mindful of parents being fixated to their appearance in the video (P1)</p> <p>Experiencing being videoed offers reassurance (P7)</p> <p>Patience and reassurance while filming (P9)</p> <p>Reassurance the focus is strengths (P9)</p> <p>Establishing a working relationship helps to overcome concern with filming (P5)</p> <p>Reassuring about filming (P9)</p> <p>Impact</p> <p>Parents who are self-conscious don't consent to video (P7)</p> <p>Worrying about video one of the biggest barriers (P7)</p> <p>Parent worrying about seeing themselves impacting on engagement (P8)</p>

Appendix 14: Extract from a memo about the process of change

The process of change occurs in the context of a therapeutic relationship. This is used by guiders to model parenting skills, but also to attune to parents. Attunement is modelled, and the parents have an experience of attunement. Is this a new experience? They want to (consciously or unconsciously?) recreate this for their child.

Process of change seems to feed in to itself. When parents feel more confident, they are more able to see / notice the successes in the filmed interaction. It is circular, and self-perpetuating.

The visual aspect helps to compensate for language difficulties, and see exceptions (link with narrative therapy?). It also provides evidence of change. Different to evidence of limitations, which are often shared in meetings with social care etc.

Appendix 15: Visuals used to orientate service users to VIG, a simplified table of recommendation for VIG guiders, and a summary of the feedback from parents.

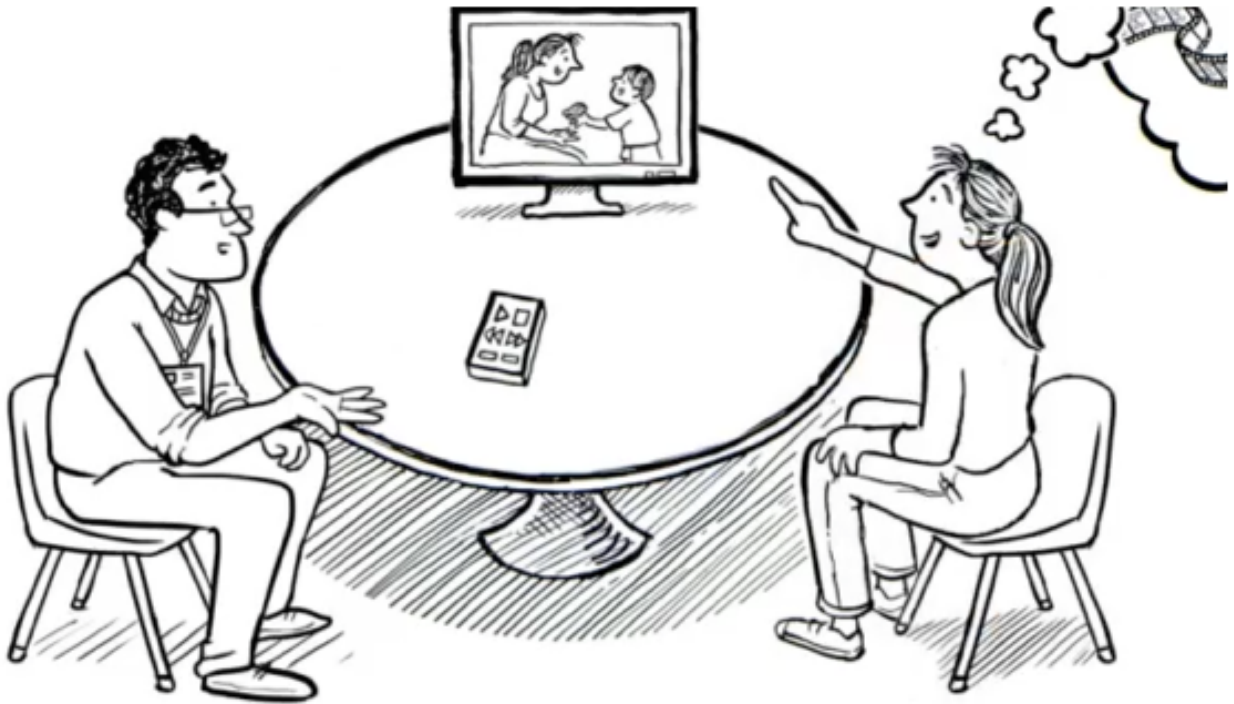
First, parents meet with the VIG guider and talk about what they would like help with.



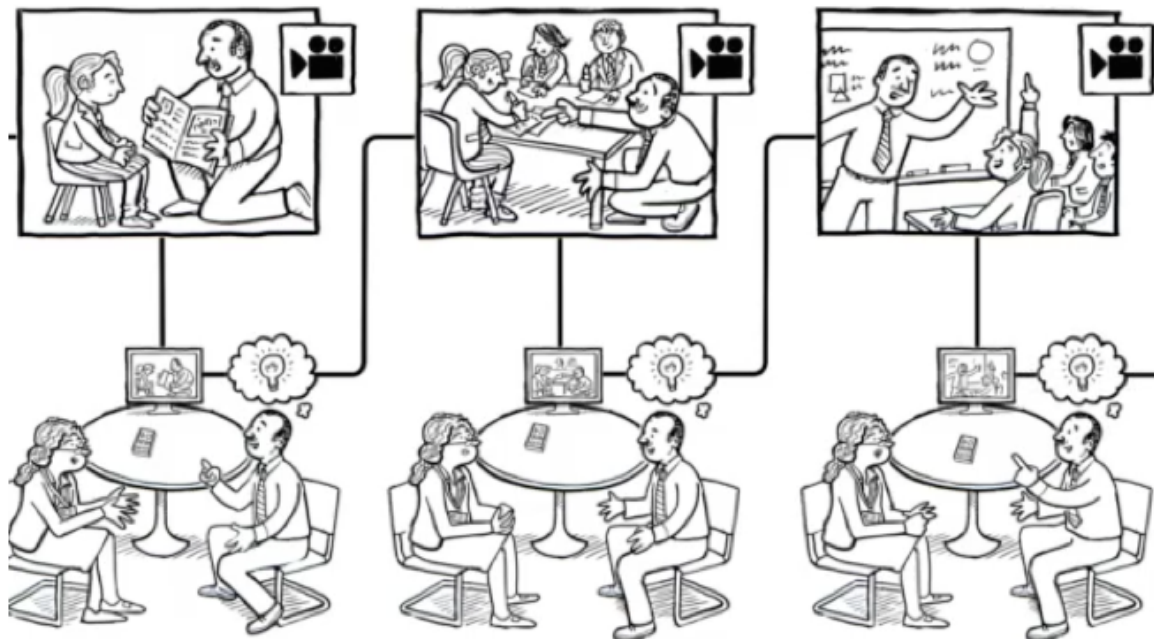
Then the VIG guider films the parents doing an activity with their child.



Then they watch the video together and talk about all the good things they can see in the video.



The parent and the VIG guider do filming and watch the film a few more times. This helps the parent to reach their goal.



Challenges	What professionals can do
- Some parents have had bad experiences with professionals	- Do be patient and kind
- Some parents find language difficult	- Do use pictures and speak slowly
- Some parents find pictures patronising	- Don't think every parent is the same
- Speaking about children can be emotional	- Do help parents to speak about their emotions
- Professionals sometimes think people with learning disabilities will not be good parents	- Do share with social workers when parents are doing well
- Some parents have low confidence	- Do focus on what parents are doing well
- Sometimes it can be hard to know how to be a good parent	- Don't tell parents what to do - Do help parents learn what to do
- Some parents can feel lonely	- Do help parents to meet other parents who have learning disabilities

Summary of service user feedback:

- In general, there was agreement that these were common challenges faced by parents with ID, and there was support for the recommendations to professionals.
- The parents liked the idea of VIG. None of them had had a VIG intervention, but thought being filmed would be helpful.
- Parents were concerned that VIG would not capture the reality of parenting. There was an idea that their children may “behave nicely” when being filmed, and the VIG guider wouldn't understand the difficulties they face on a daily basis. This idea was not identified in the research, highlighting the importance of capturing the voice of parents.
- Some parents in the service user group felt that professionals using pictures was patronising, while others felt pictures helped their understanding. This supports the importance of taking a person centred approach when making ID specific adaptations.
- Parents felt that professionals were often “too nose y” and focused on the past. They liked the idea of VIG focusing on the present in the filmed interaction.
- Parents felt that emotional expression would cause professionals to think that they were not good parents. They felt professionals needed to be sensitive and understand that crying doesn't indicate incompetence.
- All parents felt that someone in their life thought they would be incompetent parents, including family members, professionals and people in their communities. This supports the existence of a narrative focusing on parenting limitations.

Appendix 16: Final version of theoretical and focused codes, with the number of participants contributing to each focused code

Theoretical codes	Focused codes	Examples of initial codes
Pre and early VIG		
Parents and parenting before VIG	Parents' view of parenting, self and child N = 4	Before VIG – seeing parenting as task orientated and less relational (P2) At the beginning, parent didn't think children liked her (P8) Parent feeling different because of ID (P1) Being terrified of saying something wrong (P4)
	Parenting skills before VIG N = 4	Parent being uncertain of basic skills (P1) Before VIG – parent shouting a lot (P2)
	Negative expectations N = 4	Parent expecting to be criticised (P4) Parent expecting to be told what they're doing wrong (P2) Parent feeling unable to do VIG (P6) Parents unhappy with experience of other interventions (P5)
	Concerns about filming N = 7	Filming feeling intrusive (P9) Filming feeling intimidating (P2) Scared about being filmed (P1) Scrutiny from services creating concerns about videoing (P4) Worrying about video one of the biggest barriers (P7) Helping parents understand video will be used positively (P8)
Engagement	Difficulties with engagement N = 7	Parent avoiding intervention sessions (P2) Parent not wanting to look at video (P6) Mental health or ID impacting on engagement, couldn't focus (P8) Going too quickly for parents (P6) Needing more time to persuade parents to engage (P8)
	Factors which improved engagement N = 9	Focusing on positive helps establish relationship (P9) Experiencing the intervention as non-threatening (promoting engagement) (P4) Making parents feel secure in early stages (P9)
During VIG		
Process of change during VIG	The visual aspect of VIG N = 9	Parent seeing herself as successful (P4) Parent seeing own progress, wants to do more (P3) The power of seeing yourself, of seeing interaction with child (P1) Showing exceptions (P1) Parent noticing things they hadn't noticed before (P7)

		Visual aspect overcoming difficulties with language (P7) Being able to see it, evidence that it has happened (P6)
	The emotional aspect of VIG N = 8	Seeing video, overwhelming positive emotion (P8) Emotions during shared review being catalyst for therapeutic change (P7) Sadness during the shared review (P7)
	Sharing success N = 7	Using positive reinforcement charts (P4) Sharing successes, acknowledged by professionals (P4) System reinforcing with authority (P8) Parent wanted to share VIG videos with system (P3) Parents and guider wanting to share positive with social care (P6)
	The therapeutic relationship in the process of change N = 9	Modelling in the shared review, receiving initiatives (P4) Guider is a parent to the parent (P5) Modelling attunement in the therapeutic relationship (P7) Two emerging relationships, showing how it feels (P9) Giving parents choice (P3) Parents experiencing a different power balance (P2) Putting parent in control, guider stepping back (P4) Confidence to express different opinions, happens with VIG but not other models (P9)
A new narrative	Parents' changing perception and understanding of their child N = 9	"I did this", acknowledging own role (P3) New sense of self (P9) Seeing something different in themselves (P5) Parents narrative changing (P9) Parent seeing themselves as more competent (P6) Increased parenting confidence (P7) Second filming, parent having confidence to play with child (P9) Cycle of increasing confidence, changing behaviour, increasing confidence (P11)
	Parents' changing perception and understanding of their child N = 7	Thinking about how the child is feeling (I1 P2) Encouraging reflection on child's internal world (I7 P8) Moving from seeing child as challenging to kind and helpful (I1 P8) More positive explanations of child's behaviour (I4 P8)
	Parents' changing perception and understanding of their relationship with their child N = 5	Using positive language to describe relationship, leads to positive language about child (P9) Parent noticing relationship improving (P6) Discussing giving time and space to baby to help baby learn (P9)
	The impact of a new narrative N = 3	Changing appraisals of child's behaviour, impacts parental response (P7) Thinking differently led to parent being more proactive (P9)
Post VIG		
Outcomes of VIG	Impact on child development N = 3	Child's language increasing (P3) Child increasing verbalisations (P4)

	Impact on the parent-child relationship N = 7	Child seeing parent as fun to be around (P2) Improving relationship (P3) Feeling closer to baby (P1)
	Improvement of parenting skills N = 9	Parent using imagination to help behaviour (P2) Increasing attuned behaviours (P4) "He understand me and I understand him" (P7) Parent mentalizing intrusiveness (P6)
	Impact on parents' relationships with the wider system N = 6	Parent gaining insight into where ID impacts parenting (P3) Outcome – identifying parenting support needed, parenting course (P4)
	Limitations to outcome measures N = 4	Parents struggling with pre VIG measures (P1) Increasing trust in system not captured on outcome measure (P3) Open ended questions and reflecting on this helpful for pre/post measures (P2) Needing to adapt paperwork (P3) Counting attuned interaction in video better outcome measure (than questionnaires) (P4)
The impact of ID on VIG		
Parents' ID makes the intervention difficult	Difficulties with expressive and receptive language N = 8	Limited vocabulary for emotional experiences (P2) Parents giving yes/no answers (P6) Difficulty understanding VIG language (P1) Introducing attachment language can be a struggle for parents (P9) Parent not able to talk about change (P4)
	Difficulties with memory N = 2	Difficulty remembering previous sessions (P5) Recalling sessions can be difficult (P4)
	Difficult with abstract thought N = 4	Difficulty understanding the goals relevant to VIG (P8) Difficulty expressing abstract concepts changing the shared review (P4)
	Difficulty with generalising learning N = 5	Difficulty generalising to different types of play (P4) Parents not understanding importance of constancy (generalisation difficult) (P9) Difficulty generalising due to comorbidities (P7)

	Parents' overestimation of their parenting abilities N = 4	Parents something feeling over optimistic about their parenting (IP7) Concern positive focus might lead to over confidence (P6)
Adapting the VIG protocol to increase accessibility	Using concrete learning tasks, pictures and repetition N = 7	Using writing and drawing to help retain information (P2) Using thought bubbles on still from film (P4) Watching again and again (P5) Repeating video to encourage reflection (P3) Having the clips aids memory (P3) Giving still images as a reminder (P7)
	Going slowly and having more sessions N = 7	Going slower, doing more sessions (P7) Going slow, sitting back, allowing parent time to draw conclusions (P3) More sessions (P9)
	Using simple language N = 8	Using simple language (P1) Waiting for parents 'language (as VIG language can be complex) (P7)
	Modelling parenting skills N = 3	Adaptation – modelling play (P4) Modelling parenting skills (P1)
	Managing overestimation of parenting skills N = 3	Weaving in positives with negatives (P7) Reflecting on differences between video and real life (P8)
	Promoting generalisation N = 5	Formulating difficulty with generalising is important (it's an individual difference) (P7) More session to help generalising (P4) Being more directive, helping change to be generalise outside of sessions (P5)

Contextual factors impacting VIG		
Societal narrative of ID	Negative and stigmatised view of parents with ID N = 5	Society's assumptions parents with ID are bad parents (P3) Context of difficulties and errors being highlighted (P4) Parents making few initiatives (P4) Context of LD – haven't been shown how to do it properly (P9) Having a passive approach, feeling powerless (P1)
Impact of social services on VIG	Social care has a positive impact on VIG N = 5	Social services involvement encouraging parents to engage (P3) Social care allowing guider to focus on the intervention (P4) Guider knowing social care is involved improves relationship, as guider doesn't have to manage risk (P4)
	Social care has a negative impact on VIG N = 9	Social care reducing parents trust (P4) Context of social care and feeling criticised, parent believing this (P9) Parents feeling scared of children being taken away (P1) Parent concealing difficulties (due to context) (P2) People with ID mask their lack of understanding (P9)
Individual differences impacting VIG		
Parental individual difference	Parent's own psychological needs N = 5	Is trauma preventing attunement? (P5) Mental health needs meaning diverting from VIG model (P8) Mental health difficulties make it hard to hold child in mind (P7) Addressing MH before VIG (P8) Adding other work to support VIG e.g. emotion regulation (P7)
The impact of the guider on the intervention	Guiders expectations and assumptions N = 3	Guider assuming parent wouldn't engage (P3) The expectations of VIG guider impacting upon outcomes (P2)
	Guider's inexperience N = 3	Difficult for inexperienced guiders to work with nuisance (P7) VIG guiders needing to know more about working with ID (P3) Working through challenges in supervision (P8)
N = number of participants who contributed to each focused code		

Appendix 17: Summary of recommendations for VIG guiders working with parents with ID



What works well to overcome challenges when conducting Video Interaction Guidance with parents with learning disabilities (LD)? Practice ideas for VIG Guiders.

Challenges	Possible adaptations and considerations for VIG guiders
<ul style="list-style-type: none"> - Previous experiences with services can make it difficult for parents with LD to engage with VIG. 	<ul style="list-style-type: none"> - Use a collaborative and empowering stance. - Don't assume engagement difficulties indicate a lack of readiness to change.
<ul style="list-style-type: none"> - Some parents find adaptations patronising. 	<ul style="list-style-type: none"> - Avoid a one-size-fits-all approach - Formulate each individual parents' strengths and difficulties, and make appropriate adaptations.
<ul style="list-style-type: none"> - Verbal and written language, and the abstract concepts of VIG can be difficult to understand. 	<ul style="list-style-type: none"> - Keep the videos at the centre of the intervention. - Use concrete learning tasks and lots of repetition.
<ul style="list-style-type: none"> - Emotional expression facilitates changes, but some professionals assume people with LD are poor at accessing their emotions. - Professionals may think emotional expression indicates parenting limitations. 	<ul style="list-style-type: none"> - Encourage emotional expression, both positive and negative. - Try and mentalize and attune to parents' emotions.
<ul style="list-style-type: none"> - Parents with LD are often assumed to be incompetent parents. They experience high rates of child removal from their care. 	<ul style="list-style-type: none"> - Share successes with others in the system. - Support parents and others in their support network to build a new strengths-based narrative of their parenting ability.
<ul style="list-style-type: none"> - Parents' confidence may be low and they may have internalised a belief that they cannot parent effectively. 	<ul style="list-style-type: none"> - Focus on times parents have shown positive parenting skills - Challenge parents' negative view of themselves
<ul style="list-style-type: none"> - Parents with LD may have limited parenting skills, which can cause anxiety in the filmed sessions. 	<ul style="list-style-type: none"> - Spend time modelling parenting skills.

- Parents may find it difficult to process lots of new information.	- Have shorter sessions and go more slowly.
- Some parents find it difficult to generalise their learning to different type of interaction, or to different settings.	- Spend time helping parents to generalise. Generalising can be improved by conducting VIG at home / in the environment you want them to use the skills, and focusing on different types of interaction.
- Parents may have limited insight into their parenting needs. The positive focus of VIG can lead some parents to believe they don't need support, leading them to disengage.	- Sensitively encouraging parents to reflect on the difference between their everyday parenting and the parenting in the filmed interaction can be helpful.
- Parents with LD are at increased risk of mental health difficulties, and these may be underdiagnosed.	- Parents' mental health needs should be adequately assessed and supported.
- Guiders inexperience and negative expectations when working with parents with LD can impact on the intervention.	- Services should provide supervision and a safe space to reflect on the difficulties of working with parents with LD.
- There may be risky parenting practices.	- Draw on support from social care. This allows guiders to focus on the intervention rather than managing risk, and enables a strengths-based approach.
- Social care involvement can make parents feel scared, and lead them to mask their difficulties.	- Guiders could reflect with parents about their experiences of social care, and formulate the impact of this on the intervention.
- Parents with LD are often socially isolated which impacts upon their mental health, parenting skills and increases risks for their children.	- VIG can increase insight into parenting support needs, and a good experience of the intervention can encourage parents to seek more support, for example attending parenting groups. Guiders should encourage engagement with other services.
- Outcome measures may not capture change for parents with LD.	- Use a flexible approach to assessing outcomes.
- A group of parents with LD fed back that they thought VIG guiders wouldn't understand the challenges they face.	- Validate challenges while focusing on parenting strengths.

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