

**Learn With Us: An evaluation of a film-based training intervention for
support workers of people with intellectual disabilities**

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Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

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Overview

This thesis examines the interactions between family carers and formal carers of individuals with intellectual disabilities (ID). It is presented in three sections.

Part one is a review of the literature, examining the nature of the relationship between family and formal carers, as perceived by family carers. The literature review revealed that some family carers had supportive and collaborative relationship with formal carers. Yet, the majority of their experiences were defined by a lack of involvement and partnership working.

Part two presents the empirical paper, evaluating the impact of the Learn With Us (LWU) training on concepts such as empathy, conflict management, complex decision-making skills related to partnership working and choice and best interests of service-users. The LWU training was perceived as helpful, with suggestions for improvements made. Preliminary outcomes indicate that the training was successful in improving post-training empathy levels but did not affect complex decision-making skills. At three months follow-up, there was an increase in perceived conflict from formal carers' point of view. However, only a small number of participants engaged in the follow-up and therefore results need to be interpreted with caution. Finally, nine interviews with participants were also conducted at follow-up.

Part three is the critical appraisal, where I reflect on the process of conducting the research, choices made during the research and the challenges faced along the way. Additional limitations and implications of the study are also explored.

Statement of impact

The following research evaluation comes at a time where family carers' input is being increasingly recognised as valuable for both service development and delivery. The intellectual disabilities field in general stands to benefit from an intervention that has the potential to increase empathy, collaborative work and perspective-taking. This type of study highlights the importance of training sessions that showcase client testament and examples of lived experiences. Furthermore, the services adopting Learn With Us (LWU) stand to benefit from the evaluation as they can encourage and endorse the implementation of this training based on the results of this study. The developers of LWU will gain insight into the benefits and limitations of the workshop which will aid in ameliorating the training and building on its strengths. This is a pilot study therefore more research into the implications of the training need to be examined on a broader service and organisational level.

On a larger scale, all formal carers should have regular contact with family carers, particularly those who have responsibilities for providing services and support using a family-centered approach. Therefore, by examining concepts of empathy, conflict, and complex decision making before and after the LWU training, formal carers have an opportunity to advance their practice and service delivery. Finally, on an academic level, this study expands on the minimal ID carer literature that exists and generates suggestions on how to implement change and promote strategies to increase family and formal carer engagement in various settings.

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Part One: Literature Review

A systematic review of the nature of the relationship between family carers and formal carers of people with intellectual disabilities and autism: Perceptions of family carers

Abstract

Background

Family carers' perceptions of their relationships with formal carers is an important factor that constitutes the foundation of good service delivery. The purpose of this review was to shed light on the nature of the relationship between family carers and formal carers of people with intellectual disabilities (ID) and autism, as perceived by family carers.

Method

Using a PICOS approach, a total of ten articles were identified from PsycInfo, Medline, Scopus and CINAHL. Details of the studies were extracted and their findings analysed using thematic synthesis.

Results

Five themes were identified in the thematic synthesis of the articles included, describing the relationship between family carers and formal carers: 1) empowering relationship; 2) disempowering relationship; 3) dependent relationship; 4) relationship as an identity; 5) triadic relationship.

Conclusion

This review suggests that family carers longed for experiences of partnership but only a minority consistently experienced collaborative relationships with formal carers. Participants valued honest communication and information sharing. They also felt empowered and supported by formal carers who advocated for them and their relatives.

Introduction

Family carers save the UK economy approximately £132 billion annually (Carers Trust, 2018), which constitutes more than the NHS budget for England. As such, family carers' views as to what factors lead to an effective relationship with formal carers and services is both economically and organisationally valuable, as well as crucial to effective support from services.

Family carers, such as parents, siblings and grandparents, play an important role in providing physical as well as emotional support for individuals with intellectual disabilities (ID) and autism across their lifespan (McConkey, 2005). They are often the individuals who liaise with support carers to arrange various services for their relatives (Weiss & Lunsky, 2011). Paid providers and support carers of people with ID are often referred to as formal carers. In contrast with family carers, they are most commonly employed by private or public services to offer people with ID support on a regular, salaried basis (Brodsky, Habib & Hirschfeld, 2003).

The nature of the relationship between family carers and formal carers has been an area of interest for researchers, particularly partnership working (e.g., Lucyshyn, Dunlap & Albin, 2002; Prezant & Marshak, 2006). Conceptualisations of the quality and significance of this relationship are shaped by the historical context (e.g., in the past, parents were at times blamed for the disabilities of their children). This relationship unfolded and changed with time (Keen, 2007). Recent approaches have recognised the importance of a family-centered stance, whereby the relative with a disability is viewed as part of a larger system. This approach emphasises the interconnectedness of the family involved and the importance of recognising the needs

of the system as a whole, not only those of the individual with disabilities (Brown, Nolan & Davies, 2001).

Research on how families experience formal services has indicated that although structural aspects such as care plans and assignment of keyworkers are important, the nature of relationships with formal carers with whom families come into contact is fundamental (Grant, McGrath & Ramcharan, 1994). This underscores the central role that cooperation and partnership play in our understanding of how family carers experience formal care.

Partnership work means sharing of information between parties as well as equal and active decision-making. It is formed through mutual respect amongst individuals who value each other's roles and experiences. Conflict in such relationships can be resolved through honest and open communication (James, 2013). Thus, it is crucial that positive interactions and partnerships are formed between service-users, family carers and formal carers. In doing so, formal carers' roles extend to supporting the individual with ID, as well as their involved family members in order to reduce conflict and optimise service provision (James, 2013).

Effective work relations

Relationships between family carers and formal carers have been noted to be most effective when they consist of genuine partnerships. In a qualitative study by Brotherson, Huer and Parette (2000), formal carers supported families the most through the creation of shared goals, mutual respect and individualisation of technological services aimed to enhance communication with their relatives. Equally, in a study that

examined the relationships between formal carers and family carers of individuals with challenging behaviours, Dunlap and Fox (2007) emphasised the importance of committed partnership work. Finally, in a qualitative meta-synthesis, Griffith and Hastings (2014) explored the views of carers of people with ID and challenging behaviours with regards to formal services and the support they had experienced. A total of seventeen studies, covering various formal services, were examined. The results indicated that the majority of services increased, rather than alleviated, the burden of care, mainly because of limited communication between family and formal carers, lack of respite and of unsatisfactory staff knowledge. Services that were viewed positively employed skilled staff who were knowledgeable of the service users' behaviours and communication styles, coupled with a proactive, transparent and honest style of interaction with family carers (Griffith & Hastings, 2014).

Therefore, factors such as perceived empathy in formal carers, flexibility in interactions or communication, and support of family involvement were valued by family carers. Evaluation of family-orientated modes of working within the ID field in the USA confirm and expand the above findings (Trivette, Dunst, Allen & Wall, 1993; Trivette, Dunst, Boyd & Hamby, 1995). These studies concluded that formal carers need to be proactive and reflective listeners so that family carers can express their personal objectives and support needs. This process increases the chances that the focus of decision-making is in the family's control. It also matches formal support to the perceived needs of family carers, and promotes strategies that lead to the development of skills among family carers which encourage self-reliance, reassurance and family cohesion (Grant & Ramcharan, 2001).

Rationale and Aims

While systematic studies have explored the relationship between formal carers and family carers in mental health settings (e.g., Wallcraft et al., 2011) and challenging behaviour settings (e.g., Griffith & Hastings, 2014), there was a paucity of evidence with regards to the nature of the relationship between family carers and formal carers in general ID and autism settings. In fact, a review by the IASSID Families Special Interest Research Group (2012) indicated that additional research is needed to improve our knowledge of the relationship between family and formal carers in the ID field.

Therefore, the aim of this systematic review was to explore the nature of the relationships between family carers and formal carers of people with ID and autism as viewed by family carers. This review also aimed to determine what specific factors family carers perceived as important to the quality of this relationship. A better understanding of these issues may provide pointers regarding how to strengthen the care triad (service-user, family carers and formal carers) within community and residential settings.

Method

Search Strategy

To comprehensively identify relevant articles, the initial search criteria included all articles containing a keyword and synonyms for each of the first three search categories based on the PICOS approach (Campbell, Cheraghi-Sohi, Chew-Graham, McNally & Methley, 2014).

Population of interest: 1) family carers of people with ID and autism of any age, gender and ethnicity; and 2) formal carers of people with ID. *Intervention/Exposure:* studies needed to concern individuals with ID or autism. *Outcomes:* descriptors of the nature of the relationship between family and formal carers. *Comparison:* irrelevant for this review because of the descriptive quality of the research aims. *Study:* could be either qualitative or quantitative design.

The search terms (or synonyms) ‘family carer’, ‘formal carer’, ‘relationship’, ‘ID’ and ‘autism’, were entered into PsycINFO, MEDLINE, Scopus and CINAHL and were combined in various ways using the Boolean terms ‘OR’ and ‘AND’. The search terms chosen were purposefully broadly inclusive to allow for a variety of results to be located. An example of a conducted search can be found in Appendix A.

Inclusion and Exclusion Criteria. For an article to be included, it had to be a qualitative or quantitative study in English (or other language as long as the article could be retrieved in English). It needed to examine the nature of the relationship between family and formal carers of people with ID or autism, from the family carer’s perspective. Family carers included were parents (biological and adoptive), siblings and grandparents. Only peer-reviewed articles and published book chapters were included.

The search did not include a time limit, as to the author’s knowledge, there were no previous systematic reviews that addressed this topic within the ID and autism field. The only review found was a qualitative meta-synthesis by Griffith and Hastings (2014) that explored the views of family carers of individuals with challenging behaviours about the specific services their relatives had received (practical issues) as well as their personal experiences of challenging behaviour. However, the review did not focus

specifically on the quality and nature of the relationship between family and formal carers.

The Department of Health (2001) defined ID as ‘a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with a reduced ability to cope independently (impaired social functioning); which started before adulthood, with a lasting effect on development’ (p. 14). The ID can be mild, moderate or severe. This definition was used for the purpose of this review. Individuals who have autism can also have ID, but not necessarily. As such, autism is defined as a range of similar ‘conditions that affect a person's social interaction, communication, interests and behaviour’ (NHS inform, 2019). Articles that addressed challenging behaviours or other disabilities in the context of ID or autism were included. Studies of family carers of children as well as adults with ID and autism were included.

Studies that did not specifically refer to individuals with ID or autism or cognitive disabilities in the context of ID were excluded (e.g., dementia or traumatic brain injury). Learning difficulties, such as dyslexia, were not included in the review. Multi-informant studies where the narratives of family carers were integrated within other interviewees’ narratives were also excluded, except for studies where it was possible to extract the specific responses of family carers.

Formal carers provide everyday care in a formal capacity i.e., paid or voluntary. Unlike health professionals, they do not offer one-off specialist assessments or interventions. Although the logical choice in this review was to focus only on the relationship between family carers and formal carers, such as support workers or

keyworkers, other formal care providers were also included due to the lack of articles that focused on this specific population. Therefore, formal carers who offered daily or regular care and support to people with ID, such as nursing staff, special education teachers and social workers were also included. When studies included a mixture of staff or professionals with (e.g., support workers) and without (e.g., doctors) daily or regular service-user contact, again, results were only included when separate results were provided for the different groups.

In some of the studies included, formal carers were sometimes referred to as ‘professionals’. The author will refrain from using this term outside of direct quotes from participants to avoid confusion.

Study selection

The selection process for studies consisted of four phases: identification, screening, eligibility and inclusion (Moher, Liberati, Tetzlaff & Altman, 2009). The inclusion and exclusion criteria detailed above were applied to the articles identified through the searches. Initially, the titles of all articles were reviewed and those that were not relevant were removed. Then abstracts were read and all irrelevant articles were removed. Full papers were acquired for the studies of interest and only studies that met the inclusion criteria were selected. References of the included studies were searched to identify further relevant studies. The PRISMA flowchart in Figure 1 depicts this process.

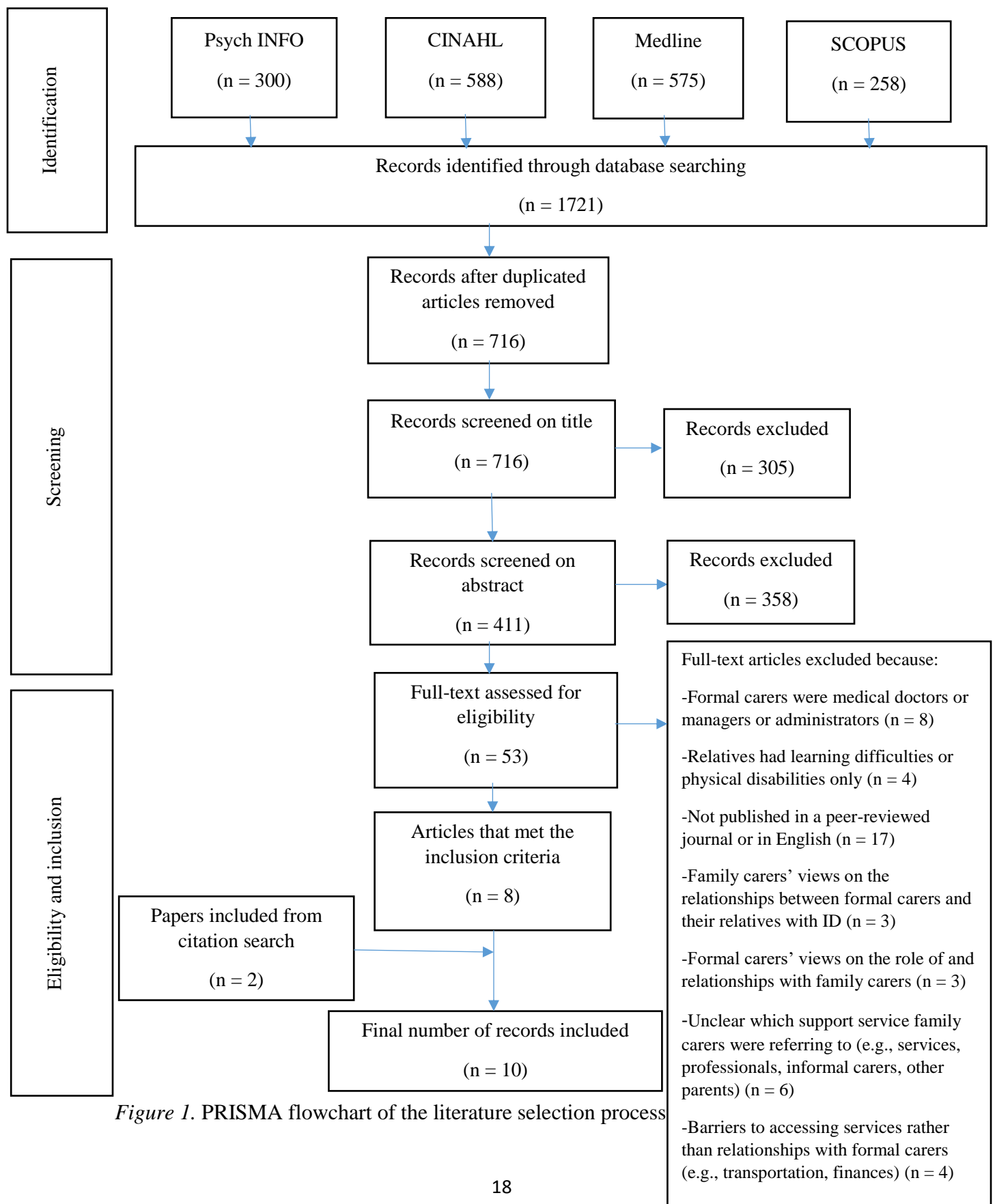


Figure 1. PRISMA flowchart of the literature selection process

Data analysis

Analysis of the included studies was conducted using a thematic synthesis (Thomas & Harden, 2008) driven by the aims of the review, i.e., to understand how family carers experienced their interactions with formal carers. This method of qualitative synthesis was employed due to its systematic and clear way of combining the outcomes of primary research (Popay et al., 2006).

The procedure was aided by the use of the qualitative software NVivo v.12, pro (2018). The synthesis was divided into three phases that overlapped to some extent: first, line-by-line coding of the results section of the included studies; second, the creation of 'descriptive' themes through grouping of codes; and finally, the construction of 'analytical' themes (Thomas & Harden, 2008).

The 'integrated methodology' approach was used in this review to combine the quantitative results with the qualitative ones. Based on the assumption that the data combined is similar enough, this methodology directly avoids separate quantitative and qualitative analyses and instead combines both types of data into a single mixed-methods synthesis (Pearson et al., 2015). This is the main method whereby both forms of data can be assimilated into a single synthesis, and in this case, since the majority of articles retrieved were qualitative, the quantitative data from Warfield, Chiri, Leutz and Timberlake (2014) were converted into qualitative statements, codified and then presented along with the qualitative themes.

The 'results' or 'findings' section of every paper was entered into NVivo. Thus, descriptions and interpretations of data from the included studies, not only participants'

quotes, were included in the synthesis for line-by-line coding. This enabled the process of ‘translation’ of concepts between studies (Fisher, Hardyman, Homewood & Qureshi, 2006). As each individual study was coded, new codes were generated and saved along with previously identified ones. At this stage, the process of translation of concepts as well as synthesis was initiated. Each phrase was coded at least once, and the majority were coded multiple times. For instance, the line: *‘She was very good that way because she made sure she gave us all the information and she would always say ‘well it’s up to you. The final decision is yours’* (Hiebert-Murphy, Trute & Wright, 2011, p.149) was coded as ‘information sharing’, ‘supportive interaction’ and ‘valued decision makers’.

Before ending this phase, the author scanned the text with an assigned code to verify consistency of interpretation and to check whether additional codes were required. This process rendered a total of 36 primary codes.

Then, similarities and differences amongst the codes were identified and hierarchies of group codes were created. This process resulted in an initial eight descriptive themes with fifteen subthemes (see Table 3). At this point, the descriptive themes and codes were verified by a second reviewer. Where discrepancies occurred, the author and reviewer debated whether the identified topic should be included as a descriptive theme. Please refer to Appendix B for a sample descriptive theme with codes.

The final stage was a synthesis of descriptive themes through the creation of analytical themes (see Appendix C). This phase has been described as the most controversial because of its subjective nature (Thomas & Harden, 2008). Here, the reviewer ‘goes beyond’ the data gathered from the studies to synthesise a broader

understanding of the research aims, in this case, of the perceptions of family carers of the nature and quality of their relationship with formal carers. From the initial eight themes identified, five analytical themes were developed: 1) empowering relationship; 2) disempowering relationship; 3) relationship of dependence; 4) relationship as an identity; and 5) triadic relationship.

Table 1

Descriptive themes and their subthemes

Descriptive themes	Subthemes
1) Conflict	a) Differing agendas b) Emotional impact
2) Power Imbalance	a) Perceived hierarchies b) Feeling excluded
3) Roles and responsibilities	
4) Service context and resources	a) Limited resources b) Undertrained staff
5) Anxieties	a) Future of relative with ID b) Care provided c) Access to services d) Relationships with formal carers
6) Partnership	a) Communication b) Active involvement
7) Family-centered care	a) Flexibility of services provided
8) Support	a) Emotional support b) Practical support

Results

The database search generated a total of 1721 records of which ten studies were retained for final inclusion in the review.

Study characteristics, design and sample

With respect to the studies' descriptive information, five were conducted in the United Kingdom, one in Canada, two in the United States, and another two in Australia. All studies were published in peer-reviewed articles. Most of the studied used a qualitative approach [n= 9]; one used focus groups, seven used semi-structured interviews, and one was a case study. One study used a quantitative approach (Warfield et al., 2014). Qualitative data analysis varied from Interpretative Phenomenological Analysis [n= 2], Qualitative Conceptual Framework Approach [n=1], Textual Analysis [n=1], Four-level Framework Analysis [n=1], Grounded Theory Approach [n=1], Constant Comparative Method [n= 1], Inductive Thematic Analysis [n=1], to unspecified thematic coding [n= 1]. Quantitative data in Warfield et al. (2014) were analysed using OLS regression, descriptive statistics and Chi square analysis.

The reported demographic information on family carers, formal carers and relatives with ID and/or autism was often limited and not consistent across studies, thus a full description of the population examined in this review does not emerge.

Family carers. Sample sizes ranged from 5 to 83 participants; the total number of participants across all studies was 369. Two studies indicated that family carers were aged 31 years or older (Hiebert-Murphy et al., 2011; Kasahara & Turnbull, 2005) and one study sampled participants aged 60 and older (average age of 68.8 in Cant, Gething,

Kending & Llewellyn, 2004). Family carers involved in the studies were parents [n= 337] (of which mothers [n= 208], fathers [n= 60] and unknown parent [n= 69]) and grandparents [n= 7]. Power (2008) indicated that the participants were family carers but did not specify which family members they were [n= 25]. According to three studies, family carers were either married [n= 74], single [n= 29], blended [n= 5] or other [n= 3].

Formal carers. Formal carers referred to in the studies included support workers as well as social workers, keyworkers, nurses, and specialists in interventions. All formal carers worked in services such as day-centres, community centres, respite services, residential services and Assessment and Treatment Units. In two studies, formal providers of care were part of a larger multidisciplinary team (James, 2015; Lawrence, 2017).

Relatives with ID/autism. The information in this section describes data gathered from eight studies as Llewellyn et al. (2004) and Power (2008) did not include the number of relatives with ID but indicated that they were adults. Family carers in the retrieved studies had 308 relatives; some of which were children [n= 288] and others were adults [n= 20] with ID and/or autism. The known number of male relatives [n=134] was more than double the number of female relatives [n= 55].

The relatives in focus presented with various disabilities such as ID [n= 133], autism [n= 34], Down's syndrome [n= 10], developmental disabilities [n= 89], behavioural difficulties [n= 7], communication disorder [n=19] and multiple disabilities [n= 16], all in the context of ID or autism. Some relatives with ID and/or autism had an additional condition such as cerebral palsy [n= 6], genetic conditions [n=8], epilepsy

[n= 1], physical disabilities [n=24], and other [n= 17]. James (2015) reported that all relatives had ID but no additional details were given. Similarly, in Power (2008), the majority of the relatives had Down's syndrome and the rest had moderate level autism but no additional specifics were given. In Llewellyn et al. (2004), 57.8% of relatives had an additional condition such as epilepsy, cerebral palsy or physical disability and 77% had a high level of disability.

Data extraction

Descriptive characteristics and the studies' main results are summarised in Table 2.

Table 2

Summary of studies included in the review

Authors (year), Country	Aim	Study Design and Sample size	Analysis	Summary of key findings
Hiebert-Murphy, Trute & Wright (2011) Canada	Family carers' views on effective support services within a government programme attempting to advance family-centered practices.	Semi-structured interviews with n=36 mothers, n=19 fathers and 3 interviews with both parents n=6. Formal carers were social workers, respite staff and keyworkers.	Qualitative conceptual framework approach. Four main themes.	Family carers appreciated flexibility and support in their relationship with formal carers, as well as information sharing and coordination.
James (2015) United Kingdom	Family carers' experiences and their relationship with formal carers at the time of their relative's admission to three assessment and treatment units in Wales.	Semi-structured interviews with n= 6 family carers (3 mothers, 3 fathers) of individuals with ID and autism. Formal carers were nurses and social workers who had contact with family carers at least once/week.	Interpretive phenomenological analysis. Five main themes.	Formal carers were considered as having an important role in how family carers experienced their sense of self, their value and contributions in the context of an admission.

Authors (year), Country	Aim	Study Design and Sample size	Analysis	Summary of key findings
Kasahara & Turnbull (2003) United States	Japanese family carers' perception of a good relationship with formal carers.	Focus groups (n=28) and individual interviews (n=2) with mothers in three target services. Formal carers discussed were intervention specialists.	Constant comparative method of qualitative analysis. Five main themes and 11 subthemes.	Family carers appreciated being respected and valued by formal carers. They wanted to be treated as equals and to have their child's best interest at the heart of the relationship.
Knox, Parmenter, Atkinson, & Yazbeck (2000) Australia	Perceptions of family carers on their control over their family lives and how their interactions with formal carers can enhance that.	Unstructured interviews based on flexible questions. N= 83 participants (68 mothers, 14 fathers, 1 grandparent). Formal carers were respite, community and residential staff.	Codes were generated from the data and themes developed. Three main themes and four subthemes.	Sense of control came from having adequate and consistent support, being equal decision-makers and continuous sharing of information.

Authors (year), Country	Aim	Study Design and sample size	Analysis	Summary of key findings
Lawrence (2017) United Kingdom	family carers' experiences of of their relationships with social workers (SW).	Four case studies (n=2 fathers and n=3 mothers). Formal carers were SW.	Four factor analysis approach.	Family carers reported that SW were mostly supportive and informative. However, they all expressed an initial uncertainty about their contact with SW as it felt like a 'power shift'.
Llewellyn, Gething, Kending & Cant (2004) Australia	Views of older family carers of their experiences in caregiving and their relationship/ involvement with formal services.	Qualitative narrative technique. Family carers (n=64) were interviewed using five pre- determined open-ended questions. One month post interview, all family carers were interviewed again. Then 3-4 months later, another interview (n=13). Formal carers were residential and respite staff.	Textual analysis. Four main themes.	Older family carers were grouped into three categories: the 'go it alone' parents wanted to be actively involved; the 'reluctant user' parents were ambivalent; and the 'tandem' parents who were less involved.

Authors (year), Country	Aim	Study Design and sample size	Analysis	Summary of key findings
McKenzie, Mayer, Whelan, McNall, Noone, & Chaplin (2018) United Kingdom	Informal carers' views and experiences of Positive Behavioural Support (PBS) offered by formal carers to their children with ID.	Semi-structured interviews and one focus group with family carers (n=8). Formal carers were residential care staff, supported living staff who were trained in PBS.	Inductive thematic analysis. Four main themes and eight subthemes.	Family carers appreciated the supportive attitudes of PBS staff. However, they felt like they did not have much control over the care of their relatives.
Power (2008) United Kingdom	Experiences of family carers trying to access services and their interactions with formal carers.	Semi-structured interviews with family carers (n=25) and informal carers (n=6). <i>Only family carers' responses were considered for this review.</i> Formal carers were SW and support workers (day care and respite).	Grounded theory approach. Three main themes.	Formal carers were experienced as non-supportive and non-informative. There was a sense of unwillingness to help. Two non-supportive interaction styles were identified as ineffective and negative.

Authors (year), Country	Aim	Study Design and sample size	Analysis	Summary of key findings
Warfield, Chiri, Leutz & Timberlake (2014) United States	Effect of the collaboration between formal carers and family carers on family well-being in an autism waiver programme.	Survey administered to 74 families (69 parents, 5 grandparents) who had been using the autism waiver programme for at least 6 months. Formal carers were support workers and intervention specialists.	Regression, descriptive statistics and Chi square analysis. Measures: Parenting Stress Index and the Relational Coordination scale.	Families' views on how well they coordinated with formal carers was associated with parenting stress and family functioning. Good collaboration led to better functioning and less familial stress.
Wodehouse & McGill (2009) United Kingdom	Family carers' perceptions of the ways in which support is unhelpful and how it could be more helpful.	Semi-structure interviews with mothers (n=13). Formal carers were specialist ID service staff (e.g., nurses and respite staff)	Interpretive phenomenological analysis. Five main themes identified.	Participants were dissatisfied with the limited information shared, difficulty in accessing service, lack of partnership and communication. They felt unheard, unwanted and blamed.

Quality assessment

Quality assessment of qualitative research has been subject to debate for many years and to this day, there is little agreement on how to conduct such an assessment, who is qualified to assess, and whether qualitative research can be validly assessed at all (Oakley, 2000; Seale, 1999). For the purpose of this study, the quality of qualitative research was assessed as it offered a more realistic view of the studies examined. However, scores should be considered tentative.

The QualSyst (Cook, Kmet & Lee, 2004) was developed to examine the quality of research studies adopting various designs. The QualSyst offers quality ratings for quantitative (14 items) and for qualitative (10 items) studies. For the purpose of this review, only the qualitative criteria were used. Studies were scored according to the ten criteria, with scores ranging from '0' to '2' (0 = No; 1 = Partial; 2 = Yes). Aspects of the study that were rated were; study aims, study design, sampling strategy, data analysis, and credibility verification. Inter-rater agreement of between 0.6 and 1 was specified for the qualitative items (Kmet et al., 2004).

For each study included, a quality score was computed by summing the individual rating scores, and dividing them by the overall possible score (i.e., 20), resulting in an individual score ranging from 0 to 1. The researcher did not specify a cut-off point for quality scores, however, the ratings gave some indication as to the quality of the articles included in this review. This scoring system was used in multiple studies (e.g, Graham, Gravel & Leare, 2006) and has been found to have good inter-rater reliability (Kmet et al., 2004). Table 3 presents the detailed ratings of each study

and overall quality scores. Quality ratings of the included studies ranged from 0.70 to 0.90, indicating reasonably high rating scores.

Table 3

Quality assessment of the nine qualitative studies included in the review using the QualSyst qualitative criteria

Study	QualSyst criteria item score (0, 1, 2) ^a										Quality score (0-1) ^b
	1	2	3	4	5	6	7	8	9	10	
Hiebert-Murphy et al. (2011)	2	2	2	1	2	2	2	2	1	2	0.90
James (2015)	2	2	2	1	2	1	2	2	2	2	0.90
Kasahara et al. (2003)	2	1	2	1	2	2	2	2	2	2	0.90
Knox et al. (2000)	1	2	2	2	1	2	1	0	2	2	0.75
Lawrence (2017)	2	2	2	2	1	2	0	0	2	2	0.75
Llewellyn et al. (2004)	1	2	1	2	1	2	2	0	2	1	0.70
McKenzie et al. (2018)	1	2	1	1	2	2	2	2	2	1	0.80
Power (2008)	2	2	2	1	2	1	1	0	2	2	0.75
Wodehouse et al. (2009)	2	2	1	2	1	2	2	2	2	2	0.90

^a 0= No, 1= Yes, 2= Partial.

^b Quality score calculated by summing scores of relevant items and then dividing this number by the total (i.e., (total individual score) / 20).

Analytical themes

The final themes identified describe the relationships between family carers and formal carers, as experienced by family carers.

Theme 1. Empowering relationship

In all studies, participants underscored the importance of having a relationship that was supportive and understanding. One of the mothers reflected on the impact of having the formal carers' emotional support: *'they dropped (name of relative) off and*

then came straight back to the house and sat down and had a cup of tea with us and talked to us. So I mean they were absolutely super' (James, 2015, p.49). Another mother disclosed: *'They're here for me as well. I can open up to them'* (McKenzie et al., 2018, p.e61).

Other family carers emphasised the pro-active support they were receiving from formal carers which impacted on their overall well-being: *'She coordinated a lot of meetings with professionals for us [...] because you know what, sometimes I was just too tired, emotionally'* (Hiebert-Murphy et al., 2011, p.150). Family carers appreciated a relationship that included emotional support and that offered them respite. They also recognised the importance of having resourceful, skilled and passionate formal carers: *'She was often an advocate for us [...] she looked for services that were available to us. She got us respite [...] If it wasn't enough she'd go back and you know and try to help us again'* (Hiebert-Murphy et al., 2011, p.149).

All participants agreed that interacting with formal carers who communicated well and listened to their concerns or ideas was a catalyst to partnership work. They emphasised the need for dialogue and reciprocal respect which would only be possible through a willingness to empathise with the other person's point of view: *'I feel I can express the various needs that I have and have those needs and feelings respected and have her do everything that she can to try to help meet those needs'* (Hiebert-Murphy et al., 2011, p.148).

In all studies participants agreed that they wanted to be 'consulted' and 'equal partners' in the relationship. They perceived collaborative work as an active involvement between family and formal carers, in which both parties contribute in

discussions and final decision-making (Kasahara & Turnbull, 2003). Additionally, in Warfield et al. (2014) the statistical analysis showed that family carers who perceived their work with formal carers as collaborative were less likely to experience familial stress and reported better overall well-being.

Honesty and openness were other qualities that family carers appreciated in their relationship with formal carers. While they believed that formal carers needed to be skilled enough to understand and help their relatives, they also appreciated honest communication when things were problematic: *'they in fact talked openly about the fact that it was difficult for [relative], to detach what behaviours belonged to the autism, what behaviours belonged to the learning disability and what behaviours belonged to the mental health problems'* (James, 2015, p.49). Family carers emphasised that they did not expect formal carers to be perfect at their job. They wanted them to have 'humane qualities', as they appreciated that their role was demanding and tiring (Kashara & Turnbull, 2003). However, their main concern was being honestly informed about any decisions and changes with regards to their relative's care.

Most participants spoke about the importance of being valued, especially when it came to their knowledge and expertise in their relative's care. They regarded a supportive and empowering relationship as one that is based on an acknowledgment of the various contributions that each carer can offer: *'They'd [the current provider] taken everything, my views... they'd taken everything into consideration, then put everything into place, then moved them'* (McKenzie et al., 2018, p.e61). Family carers were confident that their knowledge of their relative was valuable. They also realised that this knowledge coupled with the technical and professional skills of formal carers could lead

to good overall outcomes: *'Some of the things that we suggested to put in place proved to work. Cos, obviously, we know [relative]'* and *'the staff there have excellent knowledge of autism so they're very calm [laughs]'* (McKenzie et al., 2018, p.e61).

Theme 2. Disempowering relationship

While many participants valued the support offered by formal carers, a number of participants believed that most collaborative or partnership work with formal carers was an outcome of their assertiveness and perseverance. One participant reflected: *'We only get it because we are pushy and assertive'* (Knox et al., 2000, p.23). Family carers in all studies reflected on the impact of power and hierarchies in the system of care. Most tended to feel at the bottom of the hierarchy, as 'devalued' and undermined: *'[formal carers] don't always take on board what you have to say because you're just a mother, and I felt that throughout my life actually . . .'* (James, 2015, p.42) and *'as a parent, you're always second class'* (McKenzie et al., 2015, p.e60).

Family carers were not always perceived as important contributors in the decision-making process related to their relatives' lives: *'the two of us [parents] were completely ignored because he [formal carer] had his own agenda, he knew how he wanted what he wanted to do, and he just carried on regardless'* (James, 2015, p.42). Some participants went further by accusing formal carers of purposefully disagreeing and devaluing their thoughts and contributions: *'It was like as if you know you said something and he went totally against it'* (James, 2015, p.42).

Limited involvement and the lack of invitation by formal carers to participate in decision-making was a major theme in the studies. There was a sense of hopelessness

and powerlessness in some of the participants' statements: *'I was trying to get my head around the fact that we had to carry on with what he was doing, and that he was the expert and we weren't, . . .'*' (James, 2015, p.44). This power imbalance left family carers feeling unheard, unappreciated and frustrated. Having little control over the situation of their relatives was described as one of the most difficult experiences for family carers. Conflict in the relationship emerged and participants felt they had two choices in those cases, either to take matters into their own hands: *'I'm studying psychology now . . . I thought I'm not getting help from anywhere else so I'll have to do it myself'* (Wodehouse et al., 2009, p.650), or to relinquish: *'you give up after a while, when someone's not actually listening'* (Wodehouse, et al., 2009, p.649). Participants described the 'fight' for control as draining, exhausting and stressful for everyone in the family, especially them: *'Made me very ill. . . . I ended up on medication towards the end of last year for a depressive illness'* (James, 2015, p.47) and the participants' willingness to engage or collaborate with formal carers decreased.

Theme 3. Relationship of dependence

While family carers appreciated being consulted and included in the care of their relatives, they described having to rely on formal carers for things such as respite, implementation of decisions and support. This was particularly true for older family carers who were worried about the care of their relatives in the future (Llewellyn, 2017). In fact, they noted that formal carers were a source of hope as well as fear. This anxiety was also true for family carers of young relatives. This mother's anxiety about her child being accepted to a special education school portrays this worry clearly: *'you're actually telling me that you don't know if she's going to be accepted or not?'*

And now, if she isn't accepted, where do I go from there?' (Power, 2008, p.95).

Participants felt trapped in a system that was supposed to be helpful but was also their source of worry.

Indeed, with reliance comes vulnerability. This type of relationship required caution and increased the anxiety of family carers who were fearful that their interactions might jeopardise their relative's care. A mother noted: *'Sometimes [son] would say... "Mam don't, don't, don't because I'll get the backlash"'* (McKenzie et al., 2017, p.e60). Family carers hoped for a smooth interaction with formal carers to maximise the chances of their relatives receiving the best support. As such, they reported often abstaining from making comments that might upset formal carers: *'I didn't want to become alienated with them then in terms of saying something that I didn't think was right'* And another participant reflected, *'I tried not to be critical either. I tried not to say 'look I don't like being left waiting outside' I just said okay I'll abide by the rules.'* (James, 2015, p.43).

In all studies, participants relied on formal carers to share important information with them with regards to expectations and roles. A parent reflected: *'I was nervous about a social worker coming; I mean what do they do? I didn't have a clue about what to expect. There wasn't any information about social workers back then'* (Lawrence, 2017, p.92). Participants explained that they relied on formal carers to update them on their children's well-being and on helping with access to relevant services: *'As soon as we had a diagnosis we were put in touch with a social worker [...]. She was very good when dealing with his benefits. [...]. We had plenty of information and advice'* (Lawrence, 2017, p.88).

Trust was an important component in this type of relationship as family carers felt that they needed to trust formal carers in order to be able to depend on them. One father said *'I trusted them then you know, thought well they're the professionals they know what they're doing'* (James, 2015, p.44). Thus, formal carers' skills gave them credibility in the eyes of family carers and allowed them to trust their work. However, they first needed reassurance that formal carers were not just fulfilling a job, they needed to know that their relatives were in the care of people who valued them, knew their potential and accepted them for who they were as individuals. A mother reflected on her child's intervention specialist: *'I think it is very important for professionals to present trustworthy personalities and human qualities that make us feel that we could comfortably leave our child with this person for an entire day or two'* (Kasahara & Turnbull, 2003, p.255). Additionally, trust was a result of consistent and reliable forms of interaction. Participants appreciated having a structure that they were familiar with: *'I knew I didn't have to re-learn staff behaviours and trust, because it was already there'* (McKenzie et al., 2017, p.e59). This participant underscored an important process in the formation of relationships. She emphasised that trust comes after family carers have 'learnt' what to expect from formal carers.

Theme 4. Relationship as an identity

Family carers perceived involvement, collaboration and power to make decisions as important factors that contributed to their added influence over the care of their relatives. In four studies, participants acknowledged that the nature and quality of those factors shaped their identity as carers and influenced their interactions with formal carers. In some instances, they felt valued and appreciated, which increased their self-

confidence: *'Service Z has boosted my confidence to no end. They understand me'* maintained a participant who described herself as usually *'very shy'* (Knox et al., 2000, p.23).

The nature of the relationship with formal carers influenced family carers' perception of themselves as they tried to contextualise their role in the interactions. One participant reflected on conflict with formal carers and how it affected him: *'... We're not important you know, we're only the parents'* (James, 2015, p.42). In addition to not being confident in their role in the relationship, participants were also not sure how formal carers viewed them: *'I don't think we're viewed as difficult, well we're not, I think difficult...'* (James, 2015, p.45). As such, they described having difficulty mentalising the type of interaction that was appropriate. The image they were trying to portray as family carers who were concerned for their relative's well-being, was not coming across clearly: *'I'm just sick of being seen as an over-anxious mum'* (Knox et al., 2000, p.23).

The role of being 'just a mother' or 'just a parent' (McKenzie et al., 2017, p.60) was a recurrent theme in several studies. One participant said that formal carers *'[...] don't always take on board what you have to say because you're just a mother, [...] because they do think that you are emotionally, it's coming from some emotion rather than logic,'* (James, 2015, p.42). Participants felt that being the family carer was not enough of a 'qualification' or 'role' to grant them access and influence over their relative's care. As such, their perception of their impact on the collaborative relationship with formal carers was diminished.

Nonetheless, family carers wanted to be perceived as carers who contributed emotionally as well as intellectually to the relationship *'professionals aren't the experts, they have expertise and they have very good skills but they don't have the grounded knowledge that we would have . . .'* (James 2015, p.45). However, while some were confident in their skills, others were less so and preferred to keep their contribution limited, as they viewed themselves as vulnerable to stressors: *'I might know what to do [for PBS], I just don't know how to maintain it when I'm tired, ill, frustrated, or just sick of it'* (McKenzie et al., 2017, p.e61).

Theme 5. A triadic relationship

Participants described external factors that affected the nature of the relationship they had with formal carers.

Family carers come into contact with formal carers and services as a result of their relatives' needs. Thus, the relative is central in the triadic relationship and was understandably a key focus in family carers' accounts. Family carers described wanting the best for their relatives, which sometimes 'forced' them to interact with various formal carers who could assist them in receiving the necessary support (Llewellyn et al., 2004). Family carers spoke about the importance of a good relationship between formal carers and service-users. Most agreed that this relationship greatly influenced their relationship with formal carers (Kasahara & Turnbull, 2003). In particular, family carers who experienced these relationships as positive saw them as markers of good formal care (e.g., McKenzie et al., 2017).

Other variables were governmental policies and restrictions applied to formal services. Participants were aware that formal carers had limited access to resources or faced strict service protocols. There was a sense of affiliation and unity that transpired from the interviews as family carers sympathised with formal carers' position and acknowledged the lack of control inherent in their role: *'I don't blame it on the service system. It's obviously a government issue... It's a funding issue. Yeah. They're not being given enough funding'* (Hiebert-Murphy, 2011, p.151).

Participants mentioned that they appreciated formal carers who advocated and supported service-users to gain access to the services they needed (Llewellyn et al., 2004). Participants explained that formal carers' hands were often tied when it came to higher up instructions: *'One of them [staff] said... 'I've nearly lost my job through arguing with these top people'* (McKenzie et al., 2017, p.e60). Family carers were aware that the higher the needs of their relative with ID, the more likely they were to receive formal support. Despite their appreciation for the services they were receiving, they were in constant fear of losing access to those services in the future. They sympathised with formal carers, knowing that they were influenced by macro factors affecting the offer and access to services: *'It's not that the professionals here don't know there's still continuing issues. [...] The real problem is that uh, there's others with greater issues. And limited resources, you know, the usual talk. Typical resource reduction, few personnel, greater need'* (Hiebert-Murphy et al., 2011, p.152)

Finally, there was discussion about inflexibility of services *'the system is limited... it doesn't allow [programs] to stretch more for individual family needs ... One way for everybody [...]. That's what I would say to try and tailor things more'* (Hiebert-Murphy

et al., 2011, p.152). Participants felt that they needed more individualised services that focused on both, the service-users as well as their families. They were aware that formal carers had little impact on more general service provision, however, they appreciated pro-active and understanding formal carers. They also appreciated family-centered care (Hiebert-Murphy et al., 2011) where values of partnership work took center stage.

Limitations of the studies

Most of the studies had small sample sizes, partly due to the qualitative method chosen. Some studies targeted specific populations; for example, family carers who experienced difficult relationships with formal carers (Wodehouse et al., 2009) and those who experienced positive ones (McKenzie et al., 2011). Additionally, most studies had a majority of female family carers, creating a potential gender bias. The majority of the relatives with ID on the other hand, were males. All these factors can bias the results and limit generalisability of the findings.

Most of the participants were mothers, thus the views of fathers (and grandparents) were under-represented. There were no studies included that examined the views of siblings. This might indicate that mothers are usually the main family carer but poses some concerns with regards to generalising the findings to all family carers' views. Finally, all studies recruited participants through purposive or convenience sampling. These sampling methods are usually less reliable as they allow self-selection of participants and researcher bias, which again impact on the validity of the results (Alkassim, Etikan & Musa, 2016).

Considering these limitations, the insights that these studies provide into the relationship between family carers and formal carers should be interpreted with caution.

Discussion

This review synthesised the results of ten studies that examined the relationship between family and formal carers of people with ID and/or autism. The views presented were shared by a range of family carers (mothers, fathers and grandparents) from different cultural groups (American, Japanese, Canadian, British and Australian) and age groups (31 to 80 years old), over the period of almost two decades (2000–2018). Half of the studies originated from the UK [n = 5], most used a qualitative methods [n = 9], and all utilised purposive or convenience sampling methods. Most participants were mothers of individuals with ID or autism of varying ages and diagnoses. Relatives included varied in their disabilities diagnoses and their age groups. Most relatives had an additional disability (e.g., physical or developmental). Formal carers included were support workers, social workers, keyworkers, nurses and intervention specialists. Care provided was based in community, respite, residential services, and Assessment and Treatment Units.

Overall, the results indicated that family carers' perceptions of the nature of their relationships with formal carers were affected by internal (i.e., emotional support, identity/roles), as well as external (i.e., government policies, access to services) factors. The relationships were often experienced as supportive yet lacking in involvement and collaboration. Family carers reflected on their role as carers and on their contributions to the care of their relatives. At times, they sensed that they were disempowered by

inherent hierarchies and an inflexible system. The quantitative results supported those ideas as family carers' well-being increased and stress decreased when there was good relational collaboration with formal carers (Warfield et al., 2014).

Family carers perceived themselves as dependent upon services, and specifically the formal carers they were interacting with. They were fearful that voicing their concerns might lead to negative repercussions on their relative's care. As such, this created a barrier to honest communications between them and formal carers. Additionally, family carers appreciated the importance of formal carers' input and their potential to support their families, and did not want to risk losing that support.

All studies mentioned positive aspects of the interactions with formal carers except for one study (Wodehouse et al., 2009), which specifically examined difficult relationships. Family carers felt empowered when they had good communication, information sharing and a supportive attitude from formal carers. Participants appreciated formal carers who were willing to help them and their relatives secure access to good support. However, they were aware that formal carers were under various pressures and were stretched at times. Family carers' awareness of such constraints created a sense of shared burden and empathy towards formal carers.

Partnership is an important concept in the literature on carers in general (e.g., James, 2013; Nolan, 2001). However, too frequently partnerships between family and formal carers fail to be consistent and they become a source of concern and apprehension for both (Gavin, Hall, Nelson & Summers, 2003). Dunst and Paget (1991) identified six features of partnership: shared and equal contributions, joint responsibility, collaborative work, devotion and trust, sharing information, and

consensus that family carers are the final decision makers (for children). In this study, partnership featured as a main theme but did not feature as an analytical theme. This is because family carers in the studies included touched on more foundational aspects of the relationships, such as communication and involvement. Most of the characteristics of partnership work listed by Dunst and Paget (1991) were partially achieved. For example, some family carers reported feeling emotionally supported yet, they were not involved in the decision-making process with regards to their relative's care (e.g., James, 2015; Knox et al., 2000). Thus, most family carers had not yet achieved relational 'partnership' in everyday interactions with formal carers. Effective partnership was not deemed a dominant feature of current relationships between formal and family carers.

Despite some methodological limitations, the studies included offer an insight into the perceptions of family carers of their relationships with formal carers. These results add to the limited literature on family carers' perceptions within this population.

Limitations of review

Despite the researcher's attempt at presenting a systematic review of the literature examining the nature of the relationships between family and formal carers of people with ID, bias is inherent in this kind of review. First, the primary author single-handedly carried out a systematic assessment of potential articles against the inclusion/exclusion criteria. Although final decisions of whether articles would be included in the review were made in discussion with the thesis supervisor, this was done after the preliminary sort. While further reference list searching of included studies was carried out by the first author, thorough hand searching of all articles identified in the

search was not achievable. This may have resulted in the exclusion of relevant studies from this review.

This review was limited by the small number of studies that met the inclusion criteria, and caution should be exercised in generalising these results to the wider population of family carers. Small sample sizes can be problematic when employing qualitative research within a specific population, such as family carers of individuals with ID and/or autism. Additionally, removing a qualitative study from its context risks undermining the study's integrity. Nonetheless, synthesising qualitative research can help describe a larger phenomenon and detect similarities as well as differences across a variety of situations (Docherty, Emden & Sandelowski, 1997). For example, in this review the studies included examined relationships in socio-economically and culturally diverse contexts (e.g., in Japan, Wales, and Sydney).

The search term 'formal carers' was difficult to define and confine. Searching for the different professions and services included would have been unrealistic given the time constraints. However, this means that other relevant studies could have been missed. Finally, the researcher analysed the studies included using the qualitative approach of thematic synthesis, as such, interpretation of the quantitative results of one study (Warfield et al., 2014) could have been slightly underrepresented.

Implications

The findings from the current study have implications for both, research and professional practice. The initial step of identifying the positive qualities as well as problematic issues that exist within the relationships between family carers and certain

formal carers needs to be complemented by actions. Therefore, future research should examine changes that have been implemented by services in order to promote partnership work, based on family carers' feedback. Further research into the nature of the relationships between family and formal carers can then be assessed again to see whether there will be any changes.

Further research is also needed to examine the perceptions of various stakeholders such as different family carers (e.g., siblings) and formal carers. Paying particular attention to whether they present with different points of view and concerns about the family and formal carer relationship. In this respect, future research could expand on relationships between family carers who vary in ethnicity, age, gender, family-related contexts, different forms of disabilities in their off-spring, and any other contributors that could impact on the relationship. It is important to acknowledge that the family carers who participated in the studies included were a self-selected population. Thus, those individuals might be different in their characteristics to family carers who did not want to participate in the interviews or comment on their relationship with formal carers. Future research needs to investigate the unheard voices of other family carers and the reasons behind their reluctance to contribute. Finally, this review touched on important social variables, such as 'top-down' influences and policies that impact on the relationship. Future research that specifically targets this area would help our current understanding of the wider impact of external policies on micro-level interactions (e.g., service policies and regulations).

In terms of clinical implications, this review highlights the importance of transparent and open communications between family carers and formal carers.

Unfortunately, there is an absence of research that explores the practicalities and ways of implementing such changes. Thus, research into ways of facilitating and encouraging open communication between both parties could provide helpful ways for formal carers to engage with family carers and vice versa (e.g., workshops or informative meetings).

Conclusions

According to James (2013), partnerships are formed between individuals who have open and honest communications as well as trusting and supportive relationships based on empathy. In this review, participants were longing for these experiences but only a minority of family carers developed such relationships with formal carers.

Formal carers supporting individuals with ID and/or autism need to consider the nature of the relationships that form between them and family carers. In this review, formal carers who adopted a family-centered approach were appreciated and valued by family carers. Family carers who had good relationships with formal carers reported better overall well-being and reduced conflict, mainly because the support they received had a positive effect on their relatives, themselves and the system as a whole. In contrast, family carers who were dissatisfied with the style of interactions reported a negative impact on the whole family system.

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Part Two: Empirical research

Learn With Us: An evaluation of a film-based training intervention for support workers of people with intellectual disabilities

Abstract

Background

The Learn With Us (LWU) is a half-day film-based training programme developed by family carers of individuals with intellectual disabilities (ID) in partnership with Islington Social Services. It is delivered to ID services' support workers and co-facilitated by a family carer and a service manager. It was designed to help improve partnership working and increase understanding between family carers and support workers. The primary aim of this research was to evaluate the outcomes of eight training sessions on empathy, conflict, and complex decision making skills.

Method

The immediate and longer term impact of the training were evaluated using a mixed methods design. An empathy scale and situational judgment tests were administered at baseline (n= 50 and 68 respectively), post-training (n= 49 and 67 respectively) and three month follow-up (n= 17). The Interpersonal Conflict Scale was administered at baseline (n= 68) and follow-up (n= 17) only. In addition, qualitative interviews were conducted with nine participants to explore their views on the training and implications for future use.

Results

This study adopted a repeated measures design. Support workers' empathy towards family carers increased after the training, but this change was not maintained in the subsample assessed at follow-up. Perceived conflict between family and formal carers increased between baseline and follow-up. Finally, participants' judgements of

the most appropriate ways to manage partnership working and decide on choice vs best interests of service-users, did not change post-training. Five overarching themes were identified from the interviews.

Conclusions

This uncontrolled pilot suggests that the LWU programme may generate increased empathy and collaborative work between family and formal carers. This was confirmed by interviews which suggested that this programme was seen as both innovative and as having the potential to lead to change in everyday care practices.

Introduction

Family carers have always played a central role in the lives of people with intellectual disabilities (ID), either as life-long carers, advocates or campaigners for change in policies and service provision. In the UK, more than six million family carers potentially save the Government £132 billion a year in estimated care expenses (Carers Trust, 2018). This in itself is an important reason for empowering family carers, and yet most of the focus is on service-users alone, with insufficient value accorded to the care systems that support them (Hervey & Ramsay, 2004). In addition to the cost argument, there is a clear practical and moral imperative for involving family carers who have their loved ones' interests at heart. Thus, there needs to be a shift in the prevailing culture to one in which family carers are perceived as partners with lifelong experiences of providing support. In more recent years, research and advancement have focused on creating innovative ways of involving families in the care system (e.g., Care Act, 2014).

One way of doing so is by encouraging family carers to co-facilitate training. In fact, research has shown that, when family carers are involved in educating and training individuals who provide formal services, this can lead to positive results for them, for participants and for employers (Carers Matter Everybody's Business CMBE, 2012).

Learn With Us (LWU) is a film-based training package produced by family carers in partnership with support staff and their managers, and funded by Islington Social Services Learning and Development Team. Its primary aim is to enable families and formal carers, particularly support workers, to understand each other better and improve partnership working to ultimately benefit people with ID. The half-day training starts with a brief introduction to the topic by a family carer and a service manager, who

have experience of running the training. Then, the film presents segments of interviews with five family carers, multiple managers and support workers. A group of maximum 10 participants are invited to reflect on how to manage issues such as choice and best interests and disagreement with family carers through two group activities and various discussions.

Support workers' roles consist of offering support services to service-users through face to face contact in community and residential settings (Allsop & Saks, 2007). The primary aim of this study was to evaluate whether LWU may be successful in fostering empathy, interpersonal conflict management, and complex decision making skills in support workers, who as part of their work, interact with family carers of people with ID. To date, almost no training resources exist in this area.

Evaluation of training

An evaluation is a type of assessment that helps determine the effectiveness of an activity in order to evaluate its impact, the added value of participating in that activity and to assist future decision making (CMEB, 2012). For instance, training evaluations track the development of participants' knowledge, the acquisition of skills and behaviours and their application in the workplace (CMEB, 2012). By far the most common and influential approach to date is Kirkpatrick's (1976, 1994) model of training evaluation. The model is structured around four levels, each addressing complementary aspects of training outcomes: Reaction, Learning, Behaviour and Results.

The Reaction level examines the immediate subjective opinions of participants in response to a task or activity, and what they enjoyed and/or disliked about it. Importantly, this level does not evaluate any learning that may have materialised (Beech & Leather, 2006). This level was captured at the end of the LWU training by asking participants about their impressions of the training. However, it was not incorporated into the present research.

The Learning level measures the extent to which participants achieved learning objectives and acquired the intended knowledge and skills delivered in the training (Beech & Leather, 2006). Kirkpatrick (1994) suggested that various aspects of experimental research design are suitable at this level, e.g., using a repeated measures design to assess each learner. In the present study, this level was measured through Likert scales examining empathy and interpersonal conflict at different time points.

The Behaviour level refers to training transfer— the effects of training in terms of on-the-job performance. This level of evaluation is more complex than the previous stages. Behavioural tests are advocated for skills acquisition (Beech & Leather, 2006). While a test of actual workplace behaviour was beyond the scope of this study, support workers' judgements regarding the best way to respond in work-based scenarios was used to evaluate the impact of the training. The scenarios depicted situations in which family and paid carers often find themselves in conflict regarding partnership working and decisions about service-users' choice and best interests. The author referred to this level in the study as the quasi-Behavioural level.

Results, the final level, refers to the impact of training on the whole organisation in terms of performance or set objectives. Kirkpatrick (1994) acknowledged this to be

the most complicated form of evaluation, due to the numerous extraneous influences on organisations and encouraged a participative approach. According to Boyce (2006), outcome scores can be explored through interviews to provide a more holistic representation of the experience of training. Thus, in this study, this level was assessed through subjective feedback from one-to-one interviews in the aim of examining personal, contextual and organisational impacts.

Concepts of empathy, conflict management, partnership and choice vs best interests (in complex decision making), are therefore, central to the LWU training. In order to be able to examine those concepts on a micro level, this research mapped those concepts onto the above measurable training levels. The following section explores those concepts individually to introduce a detailed understanding of their specific function within this training.

Empathy

Empathy is conceptualised as a set of responses that result from projecting oneself into another individual's state or situation. It is mainly characterised by cognitive and affective responses (Davies, 1983). Self-report measures that use Likert scales are the most commonly used tools to assess empathy. While accessible and straightforward, they are a potentially biased source of information as they rely on self-reports. Judgements about the reliability of their conclusions are facilitated by comparisons with other sources of information, such as video observations or Situational Judgement Tests (Gerdes, Lietz & Segal, 2010).

Exploration of empathy in staff members in the ID field has received minimal attention over the years despite its importance in creating changes through training interventions (Hastings et al., 2018). In support services for challenging behaviours, family carers have noted limited empathy for their situation from staff as a main trigger for tensions and disagreements (Griffith & Hastings, 2013). Additionally, empathy is a fundamental developmental human quality closely linked with greater pro-social behaviours (e.g., offering help) and fewer hostile reactions (e.g., fewer arguments) (Di Giunta, Eisenberg & Eggum, 2010). Therefore, research and practice indicate that, with time, increase in staff empathy towards family carers should lead to better overall care (Hastings et al., 2018).

Partnership and conflict

Conflicting goals among individuals can create barriers to effective partnership work (Rush, 2004). For example, family carers may be interested in seeking better care for their relatives, plus to be more involved in care planning, and more support for themselves. Staff concerns can range from what is strictly expected of them, in terms of on the job performance, to overall service and personal development (Wallcraft et al., 2011). Hence, services are particularly vulnerable to conflict as the context and nature of interactions between family carers and staff may be difficult and stressful (Hipwell, Tyler & Wilson, 1989). Managing conflict is therefore important for fostering cohesive functioning in organisations and ultimately, for the overall quality of care (Vivar, 2006). According to Thomas (1992), ‘conflict is the process that begins when one party perceives that the other party has negatively affected, or is about to negatively affect, something that he or she cares about’ (p.653).

Nevertheless, conflict can also be constructive, as it can be catalytic to innovative thoughts, growth and positive change (White, 1998). One strategy to solve conflict is collaboration where each individual or group addresses the problem with equal concern. This strategy promotes identification of areas of agreement and disagreement, and a potential solution to the problem that involves both parties' perspectives (Vivar, 2006). Partnership is thus defined as a collaborative relationship between service-users, family and formal carers. Forms of partnership can range from information giving to service-users or family carers, and include different sorts of collaborative work such as open dialogues and involvement (Herron & Stacey, 2002).

Choice vs best interests

There is no clear and unique definition of what the 'best interests' of an individual refer to. This is due to 'best interests' subjective nature as well as the various situations that can be classified under it. Section 1 of the Mental Capacity Act (2005) sets out that:

'An act done, or decision made, [...] for or on behalf of a person who lacks capacity must be done, or made, in his best interests [...] in a way that is less restrictive of the person's rights and freedom of action' (p.2).

The Mental Capacity Act (2005) sets out that there needs to be a best interests' decision-maker and a best interests' decision-making process, and aims to put the person at the centre. Nonetheless, this process does not identify what 'best interests' should really represent and whether the individual's choice is being considered. The issue of choice and best interests becomes especially complicated when family and

formal carers find themselves trying to make ‘substitute’ decisions for individuals who lack capacity and there is little evidence about their wishes and feelings.

A move towards a more inclusive decision-making process has been under way since the development of multi-disciplinary teams and the explicit involvement of families in the care of their relatives (Houses of Parliament, 2011). This inevitably creates pressure on formal carers to act in a way that would not compromise the service-user’s integrity and freedom of choice, and to avoid conflict with other parties who might be involved in care.

Aims

The aim of the LWU training is to foster a supportive and understanding relationship between support workers and family carers. The aim of this study was to assess whether the training was successful in fostering empathy, conflict management skills, partnership and choice vs best interests decision making amongst support workers, who as part of their work with people with ID come into contact with family carers. Using Kirkpatrick’s (1994) training levels, the study evaluated Learning and quasi-Behavioural outcomes, as well as subjective Results. The study’s specific aims were to:

- Assess whether support workers show an increase in empathy towards the difficulties and anxieties experienced by family carers directly after completing the LWU training.
- Determine whether support workers’ perceptions of conflict while working with family carers change at three months follow-up. Perceptions of work-place

conflict were only assessed at follow-up in order to allow participants time to make those observations.

- Assess change in responses to partnership work and complex decisions of choice and best interests directly after completing the LWU training.
- Assess whether any changes in empathy and complex decision making skills are sustained at three months follow-up.
- Explore support workers' subjective experiences of the LWU training and its impact on their perceptions of, and interactions with, family carers at three months follow-up.

Method

Design

To capture different aspects of the outcomes and process of training, a mixed methods design was used, employing both quantitative and qualitative methodology. This particular approach became more popular in recent years due to the richness of data that complement or uncover underlying processes which might not be evident in a single method of analysis (Zohrabi, 2013).

Setting

The study was conducted between January and September 2018, in three organisations which provide specialist support for people with ID. Provider A offers supported housing and also supports individuals living in their own homes. Provider B provides support in a respite centre, day centre, and two residential care homes and supported housing schemes. Finally, provider C offers support in a community setting.

Participants

The power analysis for this study was informed by previous work by Hammond, Reid and Webster-Stratton (2001) who measured pre and post outcomes of a training aimed to increase teacher-parent bonding. The effect size for their study was $d = 0.45$, indicating a medium effect. Power was calculated using the G*Power3 software (Buchner, Erdfelder, Faul, & Lang, 2007), specifying alpha = 5% and desired power 80%. The required sample size was estimated at 41.

Participants in the present study were support workers who engaged with people with ID across two inner London boroughs. In all three settings, the LWU training was offered as part of mandatory induction. New employees were prioritised for places on the training workshops but more experienced support workers also attended.

Eight training sessions were the focus of this evaluation, with a total of 70 participating support workers, of whom 68 participants completed the baseline measures. Their average age was 34.81 ($SD = 11.27$), and 38 were women and 20 were men (10 missing). While some participants had less than a month of work experience with people with ID, the majority had more than five years. Their frequency of contact with family carers varied widely. The demographic characteristics of participants are presented in Table 1.

Table 1

Baseline characteristics of participants

Variable	Frequency	Percentage (%)
Ethnicity		
White	27	39.7
Black British/African/Caribbean	23	33.8
Asian	3	4.4
Middle Eastern	3	4.4
Other	5	7.4
Missing	7	10.3
Service		
Provider A	36	52.9
Provider B	22	32.4
Provider C	10	14.7
Length of work experience in ID services		
Less than a month	5	7.4
Less than a year	15	22.1
One to two years	6	8.8
Three to four years	9	13.2
Five years or more	28	41.2
Missing	5	7.4
Frequency of contact with family carers		
Not at all	7	10.3
Once or twice	5	7.4
A few times	18	26.5
At least once a week	20	29.4
Almost every day	12	17.6
Missing	6	8.8

Of the 68 participants who provided baseline data, 42 agreed to be contacted for the follow-up. Six participants had left the provider by the time of the follow-up study. A total of 17 participants completed the follow-up measures. Additionally, nine participated in one-to-one interviews. Figure 1 depicts the number of participants from each service at different stages of the research.

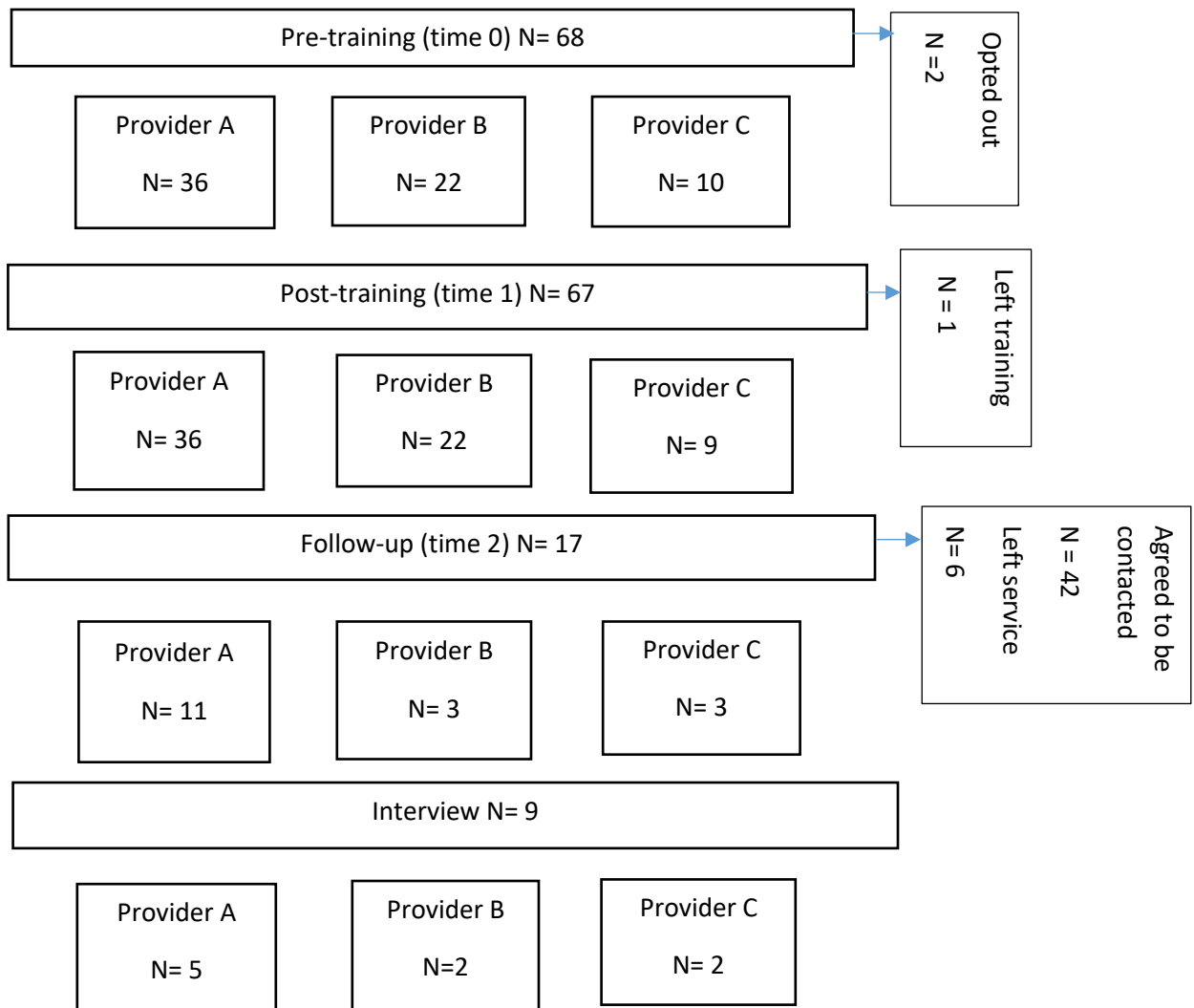


Figure 1. Number of participants involved at various stages of research

Procedure

This study employed a within subjects design, therefore, the same individuals participated at baseline, post-training and follow-up. Before the training, participants

and managers were briefed about the research purpose through an introductory email (see Appendix D). They were informed that they could participate in the training yet opt out of the research.

On the day of the training, the researcher explained the purpose of the research, the measures and confidentiality. Participants were asked to complete three baseline measures alongside basic demographic data. Following that, the three-hour workshop was led by a family carer, with experience of a training role, and the provider's service manager. The LWU film was watched in sections, followed by facilitated discussions and group exercises (see Appendix E for sample handout). The researcher was present throughout the training in an observer role. At the end of the workshop, participants were asked to complete two of the measures again. A detachable form was included to collect contact details of participants who were willing to participate in the follow-up and one-to-one interview.

Three months post-training, participants who agreed to be contacted for the follow-up study were sent an online link to Qualtrics, asking them to complete the same set of three measures. Table 2 presents the demographic information of people who participated at follow-up. Additionally, those who agreed to participate in an interview were contacted by the researcher. Table 3 shows the characteristics of individuals who participated in the interviews. The managers of each service were asked to notify participants ahead of the researcher's follow-up email in order to increase likelihood of responsiveness.

Table 2

Characteristics of participants who completed the follow-up

Variable	Frequency	Percentage (%)
Ethnicity		
White	10	58.8
Black British/African/Caribbean	2	11.8
Asian	1	5.9
Middle Eastern	1	5.9
Other	1	5.9
Missing	2	11.8
Gender		
Female	15	88.2
Male	2	11.8
Length of work experience in ID services		
Less than a month	2	11.8
Less than a year	5	29.4
One to two years	0	0
Three to four years	4	23.5
Five years or more	6	35.3
Frequency of contact with family carers		
Not at all	2	11.8
Once or twice	1	5.9
A few times	5	29.4
At least once a week	6	35.3
Almost every day	2	11.8
Missing	1	5.9

Table 3

Characteristics of interview participants

Variable	Frequency	Percentage (%)
Ethnicity		
White British	8	88.9
Black British/African/Caribbean	1	11.1
Gender		
Female	8	88.9
Male	1	11.1
Length of work experience in ID services		
Less than a month	1	11.1
Less than a year	1	11.1
One to two years	0	0
Three to four years	3	33.3
Five years or more	4	44.4
Frequency of contact with family carers		
Not at all	1	11.1
Once or twice	1	11.1
A few times	3	33.3
At least once a week	3	33.3
Almost every day	1	11.1

Measures

Participants were asked to complete a set of measures at three time points: baseline, post-training and three months follow-up. Frequency of contact with family carers was assessed by asking participants ‘how frequently do you have contact with family carers’. See Appendix F.

Quantitative.

The Staff Empathy towards individuals whose Behaviour Challenges Questionnaire (SECBQ) consists of five items rated on a 6-point Likert scale ('disagree strongly' to 'agree strongly') with higher scores indicating higher levels of empathy. The internal consistency of the scale has been found to be good– Cronbach's alpha .72 in Hutchinson et al. (2014) and .71 in Hastings et al. (2018).

The scale was adapted to measure staff empathy towards family carers. First, the sentence 'people with learning disability/autism and challenging behaviour' was substituted with 'family carers of people with learning disability/autism and challenging behaviour'. Secondly, the last question was eliminated as it specifically related to challenging behaviours. This questionnaire was completed by participants at baseline, post-training and follow-up. However, it was only administered to the participants in the last six training sessions (n = 50) as it was introduced to the questionnaire booklet at a later stage.

The Interpersonal Conflict Scale (Moore & Pillemer, 1989) examines family members' perceptions of frequency of arguments/conflicts with staff members over seven issues, using a 5-point Likert scale ('never' to 'every day'). This scale assesses conflicts during the preceding month; as such, it was only used at baseline and three months follow-up.

For the purpose of this study, an adapted version of this scale, where staff are asked to rate the frequency of conflict with family carers, was used. This scale was found to have excellent internal reliability, Cronbach's alpha of .86 in Pillemer et al. (2003).

The measure was reviewed by a family carer who was in frequent contact with support services. As the measure was originally developed for staff in nursing homes, some items were not appropriate for many of the service-users' needs, who had moderate to severe ID and were a younger cohort. Thus, the family carer's comments on the items were incorporated and changes to the terminology made. For example, 'administrative care' was substituted with 'quality of care and support'; 'laundry/clothing' with 'activities programme'; 'toileting' with 'medical issues'; 'residents' appearance' with 'communication with family'. Additionally, the word 'argument' in the instruction was changed to 'disagreement of opinion'.

The latter adaptation was made to avoid floor effects as a result of (a) a likely tendency to give socially desirable responses and not wanting to be seen as the sort of person who had 'arguments' with family carers; and (b) the idea of 'arguments' and 'conflicts' between support workers and family carers is not generally seen as acceptable within services in the UK, hence participants would be unlikely to admit such incidents but it was hoped would be more willing to acknowledge 'differences of opinion'.

Situational Judgment Tests (SJTs) are short scenarios of critical incidents that may be encountered on the job (McDaniel & Nguyen, 2001). Such tests present respondents with a situation and a list of possible responses, which they have to rank in order of perceived appropriateness to the situation (McDaniel & Nguyen, 2001). They are based on the premise that one can predict how well an individual may perform in a job based on how they perform on a simulation of the job presented in SJTs (Crafts, Hanson & Motowidlo, 1997). SJTs were found to have good criterion related validity (*p*

= .34) in predicting job performance (Braverman, Campion, Finnegan, McDaniel & Morgeson, 2001).

Development of SJTs. Usually, the situational judgment answer key is created by a group of individuals considered to be subject matter experts (SMEs, McDaniel & Nguyen, 2001). SMEs are initially tasked with generating scenarios of typical work situations. For the purpose of this study, seven preliminary simulations concerning partnership with family carers and choice vs best interests of service-users were developed by two SMEs. For each scenario, they developed five potential response options on how to handle the situation.

Then, a second group of 12 SMEs from the ID field rated the response options and commented on the draft SJTs. They included five family carers, five service managers, and four clinical psychologists. The prevalent agreement is that at least one-third of SMEs must rate the same response options as ‘most likely’ and ‘least likely’ before a scoring consensus is determined (Bergman, Donovan, Drasgow, Henning & Juraska, 2006). For the purpose of this study, the researcher increased the threshold of consensus to three-quarter of agreement. This meant that, in each scenarios, 75% of SMEs needed to score the same options as ‘most likely’ and ‘least likely’ before they were considered the ‘correct’ answers. One situation with the least consensus was dropped (Crafts et al., 1997), resulting in a total of six final scenarios used in the study.

Scoring of SJTs. Participants rated each item regarding how likely they would be to adopt the given response in the scenario presented. Each option was scored from ‘1’ (most likely) to ‘5’ (least likely). Some of the scenarios had two correct options as ‘most likely’ and/or as ‘least likely’, in line with SMEs’ judgements.

Test–retest reliability and internal consistency for SJTs with this type of instruction were found to be acceptable at $r = .67$ and $\alpha = .70$ (Ehrhart & Polyhart, 2003).

The response(s) identified as best by SMEs received a score of '+1' when rated as 'most likely' by participants, while a score '-1' was given if the response(s) deemed the worst was chosen by the participant as 'most likely', and a '0' if they chose the other two or three options. The same scoring was applied for the 'least likely' responses. Participants received a score of '+1' if they correctly identified the 'least likely' response option(s), a score of '-1' if they incorrectly chose the 'most likely' option(s), or '0' if they chose the other two or three options. The sum scores of each scenario resulted in a score ranging from '-2' to '+2', and a total individual score for the summed six scenarios ranging from '+12' to '-12'. This scoring method was similar to the one used by Motowidlo et al. (1990).

Administration of SJTs. Participants were asked to complete the SJTs within a 15-minute timeframe. This was based on a calculation of the time taken for the training itself and the fact that this left 30 minutes altogether at the beginning and end of the training session for measure completion. Participants were paced throughout to help them move through the SJTs in a timely manner. The follow-up was also timed using Qualtrics settings. In this study, the same scenarios were presented at the three measurement points but their presentation order varied to decrease potential bias of recollection.

Qualitative. A semi-structured interview schedule was developed by the researcher based on the LWU training aims (see Appendix G). It was then revised by

three independent readers who were familiar with the training and the final schedule was adapted accordingly. Before the interview began, interviewees were asked to recall the day of the training i.e., what they were doing on the day, how they were feeling before and after the training, in order to help them contextualise their thoughts.

The nine interviews were conducted and recorded by the researcher who had attended each training session as an observer. Interviews lasted between 25 to 30 minutes. The aim was to gather in depth information about the training process in general and specifically, its subjective impact on an individual and service level.

Data analysis

Quantitative analysis. Data were analysed using IBM SPSS version 25. Paired t-tests were used to compare baseline and post-intervention scores on empathy, conflict, and complex decision making skills with regards to partnership and choice vs best interests, as measured respectively by the Staff Empathy Scale, Interpersonal Conflict Scale, and SJTs, comparing time 0 and time 1, and/or time 0 and time 2 to detect any short and longer term changes. As noted above, conflict was only measured at baseline and follow-up because the scale was based on the preceding month.

In order to comply with paired t-test assumptions, all data were checked for normality and outliers. The difference between two sets of scores was computed and an analysis of normal distribution with box plots was conducted. The differences between paired scores for empathy (time 0 to time 1), and SJTs (time 0 to time 2) were neither normally distributed nor symmetrical. Thus, the non-parametric sign test was used. Additionally, one outlier in conflict scores was identified using Z-scores of variances at three standard deviations below the mean ($SD = -2.95$). Based on Aguinis, Gottfredson and Joo's (2013) recommendation, a Wilcoxon non-parametric test was conducted with

the outlier to detect its influence on the results. A paired sample t-test was also conducted without the outlier. The results remained significant and the main presented result was the one without the outlier.

Additionally, an EM missing value analysis was conducted for the Staff Empathy and Interpersonal Conflict scales. As values were missing at random, they were replaced by generated mean scores. Although SJTs had missing values, they were not replaced as the nature of the vignette style questionnaire did not allow for random allocation of scores.

In this study, independent samples t-tests and Chi square analyses were used to examine the scores of those who did and did not participate at follow-up. The findings were treated with caution due to a high dropout rate at the follow-up stage (i.e., time 2). However, they may give some indication of the impact of the training to inform future investigations.

To control for risk of type I error, only p values at the 1% level were considered significant. However, it needs acknowledging that this decision together with the small sample size increased the risk of type II error – hence, effect sizes are paid close attention when interpreting the results.

Qualitative analysis. The one-to-one interviews were analysed using thematic analysis (Braun & Clarke, 2006). Thematic analysis is a technique used for locating, analysing and organising themes within a data set. The semantic approach adopted for this research aimed to identify explicit themes without going ‘beyond’ what the participants discussed. First, the researcher immerses herself in the data by examining it multiple times (i.e., transcribing, re-reading and summarising). This process helps the

researcher generate a coding scheme for different aspects of the data set (Braun & Clarke, 2006). For the purpose of this research, line-by-line coding was aided by the qualitative software NVivo v.12, pro (2018). A total of 63 initial codes were generated from the transcripts.

Similar codes were then merged into possible themes and data identified that might fit into those themes (see Appendices H, I and J for a sample transcript, coding and thematic map). The codes and their themes were cross-checked for validity purposes by another researcher. Where disagreement about a theme occurred, there was a discussion about how to reframe. The penultimate stage required formalising the themes by naming them and defining them. A total of five overarching themes and ten subthemes were identified from the initial map. Finally, the results section presents a report grounded in the data gathered (Braun & Clarke, 2006).

Researcher perspective. My interest in the ID field, and especially carers of people with ID, stems from meeting and interacting with dedicated family carers and service managers. I was therefore keen to help evaluate this innovative training intervention that family carers worked hard to make possible. My interest and hope to see this training succeed in its goals may have influenced how I conducted and analysed the qualitative interviews. Nonetheless, I endeavoured to maintain a neutral position during the interviews and explored both positive and negative comments from participants to hear balanced feedback on the training.

Ethics

This study was approved by the UCL Research Ethics Committee (Project ID Number: CEHP/2016/551). An amendment form was granted for the addition of the Staff Empathy Scale (Appendix K). Participants were provided with an information sheet and a consent form as part of the booklet of measures and again before the interviews (Appendix L). They were also given the option to opt out from the study on the day of the training.

Results

Quantitative results. This section describes the quantitative results derived from the three questionnaires administered. Paired sample t-tests were conducted to assess the immediate and long-term impact of the intervention on empathy and complex decision making (time 0 and 2; time 0 and 1, respectively), and conflict (time 0 and 2). The non-parametric sign test was used twice, when the data was neither normally distributed nor symmetrical. Due to the large decrease in number of participants from time 0 to time 2, a comparison of demographics and baseline scores was conducted to detect any significant differences in participant characteristics.

Empathy. A sign test was performed to compare empathy scores between time 0 and time 1 ($n = 49$). The difference between the median scores was significant, $Z = -4.06$, $p < .001$. These results suggest that participants' empathy towards family carers increased immediately after the training.

The mean change in pair-wise empathy scores between time 0 and time 2 ($n = 13$) was -1.15 ($SD = 2.41$) ($CI = -2.61$ -.30). While not significant due to the small sample size, the results indicate a large increase in empathy from time 0 ($M = 20.00$, SD

= 2.71) to time 2 ($M = 21.15$, $SD = 1.68$), $t(12) = -1.73$, $p = .11$ (two-tailed), $d = 1.01$.

The results do not suggest that the significant increase in empathy scores detected from baseline to post-training was sustained at three months follow-up. However, given that this test was performed on a small subsample the results should be viewed with caution.

Conflict. In testing parametric assumptions, one outlier with a Z-score of -2.95 was identified. The value was trimmed from the data after a Wilcoxon signed-rank test determined trimming did not change the significance of the results. Both p-values were above a significance level of .05 ($p = .013$ with outlier). The mean change in pair-wise conflict scores from time 0 to time 2 ($n = 16$) was -2.06 ($SD = 2.77$) ($CI = -3.59 - .53$). This change was significant with a medium effect size: time 0 ($M = 4.21$, $SD = 4.31$), time 2 ($M = 6.27$, $SD = 4.83$), $t(15) = -2.88$, $p = .012$ (two-tailed), $d = 0.45$. These results suggest that participants were more likely after the training to experience conflict with family carers. The results need to be treated with caution as they derive from a small subsample.

SJTs. The mean change in pair-wise SJT scores between time 0 and time 1 was -0.14 ($SD = 3.12$) ($CI = -1.08 - 0.81$). The results suggest no significant change in SJT scores from time 0 ($M = 5.82$, $SD = 3.73$) to time 1 ($M = 5.95$, $SD = 3.70$), $t(43) = -0.29$, $p = .77$ (two-tailed), ($d = 0.03$). As such, carers' judgements regarding partnership work and issues of choice vs best interests did not significantly change post-training.

An exact sign test was performed for SJT scores at baseline and follow-up ($n = 16$). The results showed no significant change between the median scores at time 0 and time 2, $p = .77$. Thus, in this subsample of carers, responses to partnership work and

issues of choice vs best interest did not significantly change between baseline and three months follow-up.

Table 4

Means, standard deviations and effect sizes of paired t-test scores at baseline, post-training and follow-up

	Time 0			Time 1		Time 2		Effect size
	<i>N total</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>	<i>d</i>
Empathy ^b	49	20.00	2.71	-- ^a	--	21.15	1.68	1.01
SJT	44	5.82	3.73	5.95	3.70	--	--	0.03
Conflict	16	4.21	4.31	--	--	6.27	4.83	0.45

^a Mean and standard deviation scores not applicable

^b Item score range for empathy scale was from 1 to 6; for SJT from -2 to +2; Conflict scale from 0 to 3.

Comparison of baseline and follow-up participants. In order to examine whether the demographic characteristics and mean scores of participants who provided data at follow-up differed from those who participated at baseline, further analyses were performed.

Comparison of gender, ethnicity and age variances were conducted using Chi square analyses. There was a significant difference between women and men participating in the follow-up study, $\chi^2 (1) = 5.49, p = .01$. The odds of women taking part in the follow-up compared to men were 15:2 with a medium effect size ($w = -.31$). Comparison of variances indicated that ethnicity did not appear to have influenced participation in the follow-up, $\chi^2 (4) = 6.22, p = .18$ nor did age, $\chi^2 (27) = 34.93, p = .14$.

These results suggest that women were more likely to participate in the follow-up but that the follow-up sample was a good representative of participants' ethnicity and age.

Independent samples t-tests were also conducted in order to detect any differences between baseline scores of those who did and did not participate at follow-up. There was no evidence of a significant difference between the group baseline means of participants for the Staff Empathy scale, $t(45) = -0.23, p = .82$ (two-tailed), the Interpersonal Conflict scale, $t(57) = 0.53, p = .60$ (two-tailed), or the SJTs, $t(43) = -0.71, p = .48$ (two-tailed). These results suggest that mean baseline scores of individuals who participated at follow-up and those who participated only at baseline were not statistically different.

Qualitative results. This section explores participants' views of the training. The interviews were held at three months follow-up in order give participants time to reflect on, and evaluate the training sessions' impact on their working practices. The analysis yielded five overarching themes: 1) a novel experience; 2) what it is like to be us; 3) what it is like to be them; 4) changes in relating to family carers; and 5) implementing changes. In the following, each overarching theme and its constituent subthemes are presented briefly and illustrated with participant quotes. Participants are coded as P1-9 in order to preserve confidentiality. Text omitted from quotations is denoted as (...). Table 5 shows how many participants referred to each subtheme.

Table 5

Subthemes referred to by participants during the interviews

A novel experience	What it is like to be us	What it is like to be them	Changes in relating	Implementing changes					
Lacking in some areas	A warm experience	Culture of work	A difficult job	Daily battle	Anxieties	Genuine interactions	Empathy	Actively involving family carers	Active contributions
P1	●		●					●	●
P2	●			●	●	●	●	●	
P3	●	●	●	●	●		●		●
P4	●	●	●						●
P5	●	●				●	●		
P6	●			●			●		
P7	●			●			●	●	●
P8	●	●					●	●	●
P9	●		●		●	●	●		

1. A novel experience. Interviewees described the LWU training as a novel experience. Their accounts of attending the training are described under two subthemes.

1.1. A warm experience. Participants commented on two main positive aspects of the training. First, they spoke about the content of the material presented, stating that the videos and case discussions were emotional as well as informative. They spoke about the training presenting a realistic illustration of the struggles they faced and

'attuned to the reality of our work' (P4). Four participants compared the training to other training workshops they had attended, noting that LWU made a lasting impact on them because of its relatable content. The inviting nature of the training and the discussions that it facilitated were valued by participants. It was an opportunity to openly address certain issues they encountered in their work and interactions with family carers. The collaborative style of the training sessions signaled to participants that their opinion was valued.

'I really liked it, I thought it was different, like it's completely different than the other training I've done before, (...) a topic I've never had training in before, it was a lot of more gentle and emotional rather than sort of like numbers and facts and things like that. So, it was kind of a warm experience rather than just sort of bullet points.'
(P3)

Secondly, participants spoke about the structure of the training. The intention behind delivering the training was perceived as genuine. They particularly appreciated having family carers as co-facilitators, saying their active contribution made the experience much more realistic and valuable. It also modeled the aim of the training i.e., working in partnership with each other. Family carers' role as co-facilitators in the training reinforced the idea that they were skilled and resilient individuals, experts in their knowledge of their relatives. Beyond that, participants felt able to connect, in a non-threatening, humane way, with family carers. There was a sense of appreciation and excitement for being able to share this moment with family carers. One participant described having *'inside knowledge' (P3)* as a result of this interaction.

'I think it was great because you kind of see things from all perspectives and really you see what the aim is, it's for us to work in partnership with each other and that was like illustrated through the training course very well I think. (...) Even physically having them there at the training, showcases the fact that that's our goal to work in partnership with each other.' (P9)

1.2. *Lacking in some areas.* Despite the training session's impact, five interviewees suggested that it could be improved in two areas. First, they felt more service-user involvement would be helpful. In particular, they noted that the introduction and conclusion put the triadic relationship (service-user, family and formal carer) at the forefront yet, there was a lack of service-user involvement in both the film material and the training session. As such, they were concerned that the training might be over-emphasising family carer involvement and undermining adult service-user choice.

'Because what I remember from the training also that we were saying it's very important to involve families but it's very important as well to remember that service-users are not children, they can take some decisions and from the scenarios we saw, it was important for me that as long as the service-user has capacity to choose anything, that's the most important thing. (...). So it's a bit risky involving families too much, so I hope I will always make sure service-users have the first choice.' (P1)

Additionally, interviewees thought that the sessions needed to be treated more as a reflective space rather than a one-off session. They thought that their established style of work was similar to what was being presented. What was important to them was the emotional impact of the training rather than the acquisition of new knowledge. They

thought they benefitted from talking to other participants in the training as well as with the facilitators, and agreed that the training offered a valuable space to reflect and discuss ideas.

'I just think that it shouldn't be treated as training I think it should be a continual thing'. (P5)

'I think it's not necessarily that I've learned something new that I've taken away, it's more that you've seen behind the scenes a little bit, and to always remember what that perspective is, I guess that's what I've learned from it.' (P3)

2. What it is like to be us. This overarching theme describes the reflective stance participants adopted with regards to their role and is discussed under two subthemes.

2.1. Difficult job. Participants reflected on their role within the triadic relationship. Some felt that their job was difficult and demanding as it was and worried that they were being asked to do more than was already expected of them.

'I was thinking, how me, just me, alone by myself can fulfill all these expectations and needs. So I was quite upset thinking like, it's easy to say.' (P1)

They emphasised that their roles varied from being a service-user's support system, a family carer's helping hand, and a decision maker on behalf of both at times. They noted that the latter role can sometimes cause conflict with family carers but felt the training was particularly helpful in addressing situations where conflict arose. They said it did so by portraying real life situations that could be encountered in their everyday work and allowed them to reflect on what to do and the consequences of each course of action on the whole system.

'I remember some of the discussions that were stirred through the training and thinking, you know sometimes we are faced with really difficult decisions as support workers and it is a challenge, it is always a challenge.' (P9)

2.2. A culture of work. Participants also reflected on their personal style of working within their organisation and its work culture. They indicated that although they tried to do their best, they could understand why some family carers might be concerned for their relatives' care. The turnover rate for support workers is high and often there are temporary staff. Participants acknowledged that different styles of working can create confusion and a lack of transparency in the approach the service takes towards the care of the relative. The training helped them reflect on this aspect and some found themselves challenging what they saw as insensitive approaches or practices.

'It's weird at work because you get people who are generally, genuinely they care, and you get people who want an easy job.' (P5)

'I think it kind of makes you think like you don't agree with something, to challenge it as well, it's not what the training is specifically about, but I think recently in my job I've had one of my colleagues saying one thing to the parent, and I was like I don't agree with that, so I challenged it.' (P8)

3. What it is like to be them. This overarching theme describes participants' ability to adopt the point of view of family carers and reflect on it. Interviewees indicated that perspective taking was facilitated by the training. It is discussed under two subthemes.

3.1. *Anxieties.* Participants acknowledged that family carers often face challenging and anxiety provoking situations while caring for their relatives. The main anxieties that they could think of concerned physical/emotional safety, care provision, extent of their involvement in care, and the future of their relative. Participants spoke about the anxiety stemming from a place of 'love' and seemed to understand these worries and related to them. They acknowledged that they, as support workers, were often perceived as 'strangers' taking care of another person's loved one.

'That the people that are looking after them don't know them as well as they know them. Yea, they are not gonna love them and care for them the same way that they have fiercely been doing for their whole life, that can pose a lot of things, like what if they forget the medication, what if they don't know about this little thing that might trigger them and make them upset, and also just that they don't know the carer very well or the support worker very well personally, and they are trusting their most valuable treasure with, you know. So I think those are huge concerns.' (P2)

'It's quite sharp in the part where they spoke about sometimes they'll still dream that they pass away before them, 'cause that was, that hit home, just thinking about it now it hits home. That was quite emotional to hear that, and that's from every loving caring perspective too, that's quite a hard thing to hear.' (P3)

3.2. *A daily battle.* Most participants spoke about the struggles of having a disabled relative. First, they noted that family carers have been advocating for their relatives since they were born, from better care to more services, driven by a desire to give their relatives the best chances at feeling supported. Secondly, they discussed the social and personal repercussions of having a disabled relative. They were aware of the

limitations that being a family carer could place on a person, e.g., a reduced social life and limited choices. They also described the enormous pressure placed on family carers to care for a dependent relative.

'How boring it can become to read the same story all the time, to go to the same places, to keep the same food that the child likes... yes so, it's the social repercussion of having a disabled child.' (P6)

'I speak to a lot of them [family carers] and they say 'oh I'm so tired' 'oh I just want to go away but it's difficult' they want that break but they find it difficult.' (P7)

4. Changes in relating to family carers. This overarching theme summarises interviewees' reflections on their evolving relationships with family carers. It is discussed under two subthemes.

4.1. Empathy. Seven interviewees agreed that they felt more empathic towards family carers after attending the training. One said *'you just have to feel with them'* (P7) when describing family carers' frustrations about the struggles of being a carer. Additionally, 'difficult' family carers were perceived with understanding and compassion. Participants were aware of family carers' points of view and as such were able to relate to them more easily. Empathy helped 'diffuse' a lot of the 'head-butting' and conflict that was usually encountered on the job. When participants were able to put themselves in family carers' position they described becoming more lenient and accommodating.

'I have seen in myself the change, because I tend to be quite judgmental and I say 'well why don't they look after them better, why don't they do (...). So putting

myself in their place and saying 'okay but they do it with love, with the most they can do', I have learnt to not be that judgmental or being at least more aware.' (P6)

'I was new at the training, new at this job and new to this sector, I come from a mental health background, so I would say I was always kind of respectful and caring, but I'd say now it's more empathetic like more like understanding of what they go through.' (P3)

4.2. Genuine interactions. In their reflections about how they related to family carers, interviewees acknowledged the need to be more transparent. They spoke about honesty and trust as important elements to a good relationship with family carers. They recognised that formal carers needed family carers to trust them to do their job with the service-user, just like they needed to trust the family carer in the way they provided care. Interviewees discussed instances of feeling empowered by family carers and how validating they found this. Through genuine interactions, they hoped that they could be able to draw on each other's resources and solve difficult situations.

'One incident, I had one of my volunteers with autism, he had a really tough day and I asked if it would be okay to call his mom and we all spoke together, and I felt like that empowered me to go to them for support to help me and give me the tools that's best for [relative].' (P2)

5. Beyond the training: Implementing change. This final overarching theme summarises participants' reflections regarding what they would take forward from the training and how they might apply it in their daily interactions. It is discussed under two subthemes.

5.1. Active contributions. Participants acknowledged that actions needed to be taken in order to implement change in practice. First, conflict management was regarded as an important step towards actively contributing to a better relationship. *'It's the talking and discussions and how to step in before it escalates'* (P3). They also discussed how more communication amongst formal carers can improve work relationships and thus lead to better overall service provision. They noted that if they were able to manage the dynamics within work and present a coherent front to family carers, this could portray their investment in their roles. They thought the training helped in consolidating those skills and offered them practical solutions.

'I mean again this is kind of how you work with service-users' families but even with my colleagues I might not always agree on how best to approach things, so definitely it has kind of made your perspective change to see how to deal with those situations.' (P8)

Secondly, interviewees wanted to promote change in the workplace by encouraging other colleagues to attend the training and talking about it to their managers. For some, it sparked ideas on how to have more contact with family carers, e.g., through coffee meetings. Others hoped to have more workshops which included sharing of lived experiences and active interactions. This enthusiasm created a wave of personal responsibility for change. Interviewees said they felt able to apply the new perspective resulting from the training to their work, their interactions with family carers, and how they thought about service provision in general.

'He [manager] came out and like "oh they are not gonna let them on the course" but I was like "no they're going on this training because they need to do this

training because it's really good". And so (...) I was like determined to make sure that they go on the training because it's really good for them to get the end of it, that kind of relationship with the families 'cos in our service we are not residential we work in outreach and we work very closely with the families so that's really important.' (P3)

5.2. *Actively involving family carers.* Interviewees noted that the training encouraged them to help family carers become more involved in the care of their relatives. To achieve this, participants believed they needed to promote a culture of collaboration and partnership, with communication and listening viewed as essential elements for partnership work. They also said they felt more confident after LWU in talking to family carers and that the training helped them keep family carers in mind and involve them on a regular basis. Family carers' knowledge became a resource participants wanted to utilise.

'Hearing, listening to what she had to say, listening to what suggestion she had and then working with her (...), I felt really good talking with her in confidence, working with her for solutions 'cos I knew that she wanted him to continue to go to the group.' (P2)

Participants viewed themselves in a position of power, where they could influence the outcome of an interaction. They were aware that if they tried to involve family carers by calling them, inviting them to the service, or even just taking the time to chat to them, they could pave the way for more collaborative work. They appeared certain that the end result would be a better work experience and a more supportive environment.

'Hmm, so the first point of contact for this person is her brother and he is not really involved. So we didn't really talk with the parents until now but maybe this is something that we need to change.' (P1)

Discussion

The aim of this study was to evaluate the outcomes of the LWU programme on empathy, conflict, and complex decision making with regards to issues related to partnership work with family carers and choice vs best interest of service-users. In order to do so, Kirkpatrick's (1994) training evaluation model was adopted, to consider the impact of LWU in terms of Learning, quasi-Behavioural change, and Results immediately post-training and again at three months follow-up. In the following, the results of the present study are summarised and expanded on, and their limitations and implications considered.

Over the course of the study, a total of 68 support workers from three different providers participated in the LWU training at baseline and post-training. There was a significant decrease in participants at follow-up which could indicate that participants, particularly males, were not comfortable repeating the measures or engaging in the interview.

Support workers' scores on the Staff Empathy scale showed an increase in empathic responses immediately after the training. However, in a subsample of the population, the large increase between baseline and three months follow-up scores was non-significant. This increase in scores could have been non-significant due to the small sample size it was tested on. In fact, during the interviews, support workers discussed

how the training facilitated their ability to see things from family carers' point of view and as such increased their empathy towards them. Mainly, they spoke about an increased ability to recognise the struggles/anxieties of family carers and consequently adopt more flexible styles of interaction.

Perceived disagreement between support workers and family carers increased from baseline to three months follow-up. During the interviews, support workers spoke about conflict management and strategies to enhance effective work relations with family carers. They described genuine interactions as ones that are based on trust and transparency. Several possibilities could explain the increase in scores. First, the participants who opted to complete the follow-up questionnaires as well as engage in the interview may have been more engaged in the training. Therefore, the increase in perceived conflict might indicate that they were more aware of conflict between them and family carers after the training. A second explanation relates to social desirability. Support workers may have been less willing to admit to differences in opinions and potential conflict between them and family carers at baseline but the training may have left them more willing to acknowledge conflict. Finally, the scale was adapted from its initial format by a family carer in frequent contact with support services, rendering it more sensitive to family carers' perceptions of conflict situations. After the training, participants may have become more aware of the issues listed by the family carer, contributing to the significant increase in interpersonal conflict scores.

Responses to partnership work and decisions of choice vs best interests did not significantly increase from baseline to post-training and follow-up. During the interviews, most participants spoke about ways they could increase partnership work

with family carers and some discussed actual plans for increasing collaboration. For instance, they considered involving family carers through making more contact with them and asking for their opinions. Support workers also reflected on their role within the triadic relationship and the culture of their work environment. They were aware of some of the limitations that their services could pose, yet were motivated to actively work towards more integrative and family-centered care. According to the Stages of Change Model (DiClemente & Prochaska, 1983), when individuals are in the ‘contemplation stage’ they are considering to implement new behaviours in the near future (usually within the next six months). It is possible that at the time of the follow-up and interviews participants were contemplating the possibility of change however had not yet reached the stage of actually working in partnership and making joint decisions with family carers. Unfortunately, the researcher was unable to wait six months to re-administer the SJTs but this could partly explain the lack of change observed.

Additionally, Kirkpatrick’s (1994) model assumes that the levels of training are linked, such that positive reactions reinforce knowledge acquisition, which improve behavioural skills and positive overall results. Nonetheless, research does not support the correlational or causal linkages between the various levels (Bates, 2004; Colquitt, Lepine & Noe, 2000). This is because behavioural outcomes can be influenced by contextual or external variables that can impact on the acquired skills or competences (Arthur, Bennett, McNelly & Stanush, 1998). For example, the post-training work context may not be ideal for the acquired skills or knowledge to consolidate (Ford, Quinones, Segó & Sorra, 1992). The results of this study indicate

that some learning occurred after the training however, decision making skills did not materialise. It is therefore important to keep in mind that variables such as the culture of work might impact on the generalisation and transfer of skills. Support workers mentioned in the interviews that the different working styles amongst them and the difficulty of the job can impact on their interactions with family carers.

In a recent study by Gormley et al. (2019), the researchers tested a behavioural skills training intervention for ID staff. The results indicated that knowledge scores of participants in the intervention condition increased significantly post-training. Additionally, the knowledge and skills acquired were sustained at four week follow-up amongst participants in the intervention condition compared to the control group. The LWU evaluation did not have a control group. This could have masked some of the more subtle changes that the training sessions produced. Although the LWU training evaluation did not present evidence of long-term knowledge or skills acquisition, according to interviewees, its main impact was through its emotionally powerful content. According to Zins (2004), social emotional learning is the basis of pro-social behaviours such as empathy and perspective-taking.

‘Partners in Caregiving’ is a training programme aimed to improve relationships between families and nursing staff (Albright, Hegeman, Henderson & Pillemer, 1998). This three time, two-hour training was offered to nursing staff as well as family carers. Participants’ satisfaction in both groups was high, with an average of 99% of them stating that they had more insight into the other group’s perceptions. They also noted that their own behaviours towards the other group changed and they saw a positive change in how the other group was acting towards them. LWU was a one off, half-day

training that produced similar positive qualitative results. Support workers indicated that they were able to notice a change in their own position towards family carers i.e., becoming more reflective and considerate. They also spoke about how they were able to see things from family carers' point of view i.e., their anxieties and struggles. Therefore, there is good reason to believe that LWU was a powerful training that was able to produce change within a small amount of time.

Limitations

This study had no control group thus, the changes in scores cannot be confidently attributed to the training itself. Moreover, there was a high dropout rate at follow-up creating potential attrition bias. The number of participants at follow-up did not match the power analysis hence there is a high risk of type II error. Support workers who opted to participate in the follow-up did not have statistically different scores at baseline compared to follow-up non-completers. Yet, their enthusiasm to partake in the research and potentially their characteristics as individuals may have affected the results obtained at follow-up.

The adapted measures were not tested on a sample from the population assessed. Therefore, test-retest reliability was not evaluated. Some of the concepts that the researcher tried to capture were hard to define and potentially difficult to measure objectively (e.g., empathy, choice and best interests) and the quantitative measures selected were not able to capture the emotional impact of the training. Despite the researcher's attempt to remain independent of the intervention, interview discussions may have been influenced by social desirability. Finally, the researcher was unable to control for external factors that could have affected the follow-up results e.g., how

participants completed the online measures. For all those reasons, the follow-up results need to be interpreted and generalised with caution.

Conclusions and implications

The LWU training was perceived as a valuable and emotional training by participants. Its unique and effective format enabled participants to develop an increased understanding of and empathy towards family carers' perspectives. Support workers valued having family carers as co-facilitators and their participation appeared an important component to a successful training experience. Accordingly, the model of having family carers and service managers co-deliver the LWU training appears an important aspect at its success and should continue in the future delivery of the LWU training.

Future training sessions should include service-user input. Support workers missed this aspect and wanted to hear the opinion of some of the individuals they were caring for. The content of the training was well received but participants thought that a one-off session could run the risk of having a short-term impact. It is therefore important to consider how the discussions initiated in the training can be continued, for example, by including reflective spaces about changes staff are making in response to the training in staff meetings and supervision. The findings of this research will be formally shared with the producers of the LWU programme in July 2019. Subsequently, a summary of the study will be disseminated to the services that partook in the research study (Appendix L).

Implications for future research. Further research into the impact of the training could be beneficial as the results of this study remain tentative. First, the use of the SJTs needs to be reconsidered in future research as they may not be a reliable way to assess support workers' changes in judgement. Thus, behavioural tasks such as manager ratings of on the job performance or family carers' rating of behavioural interactions with formal carers could be more appropriate (Arthur, Bennett, Edens & Bell, 2003). Second, the use of a control group of formal carers who do not receive the training would be crucial. This will help researchers compare the groups and yield more detailed results.

Due to the interactive and reflective nature of the training, qualitative data might be more suitable to help assess outcomes. Focus groups about the training could be relevant and informative and could be held immediately post-training and again after some months. They might also allow for reflection and strengthening of the training's impact and scope for actual changes in practice.

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Part Three: Critical appraisal

Introduction

This section addresses my personal reflections on the experience of undertaking this research. It discusses my novel exploration of the area and the practical challenges faced in the development and implementation of the Learn With Us (LWU) evaluation. It also addresses the limitations and implications of the empirical study, in the hope this will assist future researchers and facilitators of LWU.

Researcher's perspective

My interest in the intellectual disabilities (ID) field, and specifically carers of people with ID, solidified while undertaking this research. As I worked alongside family carers involved in the training, I appreciated the dedication and perseverance that was necessary to implement change and foster understanding. My enthusiasm to help them in their endeavor to reach more services and spread their point of view fueled my motivation. It was also a pleasure to meet sensitive support workers who worked hard to help others in need. This research has been a rewarding opportunity which enabled me to explore the dynamics that exist within the ID carer culture.

While undertaking my thesis, I strived to keep in mind the formation and development of an 'intimate relationship' with the subject of study (Denzin & Lincoln, 1994). My reflections on this matter fell under two categories; the relationship with the research itself and the relationship with participants. In the first one, I found a sense of empowerment, a capacity to gain insight and share findings. I also felt connected to the subject I explored due to its genuine and valuable message. In the second, I reflected on my ability to 'give voice' to family and formal carers whose perspectives needed to be

heard and acknowledged. I strived to be an ‘independent’ researcher and an outsider observing the interactions between family and formal carers, but I also recognised my potential impact on the research process. I noted that my bigger role was to share the ideas and concerns of family and formal carers. I was also aware of the ‘transformative’ nature of research (Finlay, 2006) and its impact on participants. Therefore, remaining mindful of my approach to participants, and their responses to the training and the measures. Those reflections are explored further in the sections below.

Process Issues

Systematic Review

Systematic explorations of the relationship between family and formal carers in various fields, such as mental health and older adults, have received increased attention in recent years (Levesque et al., 2010; Rowe, 2012). However, this dynamic has been underexplored in the ID field (IASSID Families Special Interest Research Group, 2012). Despite the paucity of research addressing this issue, I decided to undertake a systematic review of the nature of the relationships between family and formal carers in the ID field, hoping this would complement my empirical review. Through my exploration of the literature, I recognised the need for a thorough investigation of issues related to communication, partnership and collaboration amongst carers. Particularly, family carers’ perceptions of the nature of the relationships between them and formal carers, in the hopes that this will generate ideas on how to form partnerships and decrease conflict.

The process of investigation was not without challenges. In fact, while undertaking my systematic review I found it difficult to find studies that examined the relationship

between family carers and support workers. Therefore, I had to broaden my search terms to ‘formal carers’. This included individuals such as social workers as well as nurses. Ideally, I would have preferred to examine the specific population of support workers because those are the individuals who usually interact with family carers and service-users on a daily basis.

Empirical paper

Capturing the impact of the LWU training through Situational Judgement

Tests. Situational Judgement Tests (SJT) offer an interesting and novel way of measuring behavioural responses, or rather behavioural intentions. Despite my initial enthusiasm for testing the quasi-Behavioural level through SJTs, I struggled to administer and score the vignette based measure. I encountered some conceptual issues with the measure itself, which I discussed at various points with my thesis supervisor. First, we were not aware of the level of education that support workers had. In particular, it was noted that some participants were struggling with comprehending and following the SJT instructions, even after these had been carefully explained by myself. Particularly, some individuals needed my assistance in going through the vignettes and response options. The individuals who struggled the most were generally older and mainly from one of the participating organisations (provider B, see empirical paper).

This group, was quite different in composition from provider A support workers who were newly employed, younger and probably had left college recently. The latter seemed able to cope with the pressure of a timed test. In contrast, provider B and provider C support workers were more diverse but at least half of them were older, had been working as support workers for a long time and as such were more experienced

but unused to tests. The older support workers struggled with the rating of the scenarios, putting numbers down that did not relate to the task and/or not responding to all the scenarios. As a result, not all returned questionnaires were valid or complete. This was less of a problem at post-training, when participants had learnt from the first time around how to complete the measure.

When the difficulties with the SJTs became apparent, the research team noted that the complex measure was not suitable for all participants. Therefore, information was sought from a provider B training co-facilitator who said that participants had a range of abilities (e.g., in terms of literacy, the participants ranged from someone who was undertaking psychoanalysis training to someone who struggled to read text extracts). However, the facilitator thought that overall the training workshop went well and he did not receive any complaints from participants.

Another difficulty encountered concerned the logistics of SJT administration. SJTs are usually timed because they are administered to individuals applying for a job or a course of study. Their aim is to test the individuals without giving them a lot of time to think and debate the answers. This serves to capture immediate thoughts and behavioural reactions (McDaniel & Nguyen, 2001). Timing was essential for the purposes of this research. First, because the aim was to assess immediate reactions before and after the training. But mainly because of time restraints on the day of the training. Participants had 30 minutes before the start of the training session to complete all of the measures. Therefore, they were informed that they had 15 minutes to complete six SJT scenarios. The issue of timing was carefully considered while developing and piloting the scenarios with subject matter experts (SMEs). SMEs reported that they

enjoyed rating the SJTs and that it was an interesting experience. They were asked to complete the scenario ratings within 15 minutes. Most reported doing them in 12-13 minutes. Nonetheless, they were not under the same context pressure (i.e., unlike support workers they did not have to perform in a group setting, before a training session) and were more used to academic tasks. Unfortunately, for logistic reasons I was not able to test how support workers would respond to timed tasks.

Keeping in mind that this style of testing might be too anxiety provoking for support workers who were not prepared to undertake such a complex task, and after the first training session at provider B, a couple of changes were made to the way the SJTs were administered. First, participants received a 'mock' scenario by email a long with the same SJT instructions before the training session. Then, I went through the same mock example with participants on the day of the training directly before they started the timed task. I also reassured participants at the beginning of each training session that we were not testing their competences, but rather the effectiveness of the training. Secondly, I frequently indicated to participants how much time was remaining and which question they should aim to be at. This was also a helpful strategy to pace participants. Finally, participants were asked to discontinue the exercise and speak to me or their managers if they felt uncomfortable.

Finally, SJT data entered on SPSS were particularly difficult to navigate due to 1) the amount of data that needed to be entered and 2) the nature of the scoring system described in part two of the research (e.g., computing individual vignette scores, overall individual scores, and overall baseline scores). I had a huge data set with some missing

values that could not be replaced, leaving me with unusable individual scores. This process undermined the overall scores and inherently, affected the results.

Validity and reliability. One of the issues, that was unfortunately difficult to solve, was testing the adapted measures and interview schedule with my research population. I was hoping to test the measures on a sample of 25 support workers before administering them to the research participants. However, my proposal was rejected because apart from logistic restraints, the two organisations we were in contact with were both sending participants to the training sessions, and were doing so throughout the year. Hence, they did not feel able to identify any staff who could test the measures separate from the training. It was also difficult to present this task as worthwhile for support workers and managers to give their time.

The follow-up questionnaires were emailed to participants via an online link. Unfortunately, there was no way of re-administering the measures face-to-face. This process could have introduced a significant amount of bias, especially since there was no way of ensuring that the participants were doing them alone. However, the SJTs were timed which could have helped ensure that participants were not spending more than 15 minutes on the questions. Finally, there was a high attrition rate at follow-up. This increased the study's risk of bias and limited the generalisability of the follow-up results.

Reflections

Reflexivity is a crucial step in presenting a research study. It is usually composed of a summary of the researcher's thoughts and experiences of undertaking the research.

This gives readers an opportunity to assess the potential impact of these reflections on the research (Hodges, Kuper & Reeves, 2008).

Attending the training workshops

I attended all eight training sessions hoping to observe the dynamics of the various groups. I noted several things that were helpful in doing so. First, by being present throughout the whole training, I was able to observe how participants were relating to each other, to the facilitators and the contents of the training itself. I noted that participants were mostly captured by the video interviews of family carers who told their stories. This in fact generated a lot of discussions. I also observed the facilitators' different approaches and styles of conducting the training and engaging with participants and how this affected the tone of the training. For instance, some trainers were more mindful of time and getting all the material covered, while others allowed for conversations to flow more freely.

Another notable issue was the dynamic between family carers and managers, as co-facilitators. I observed a collaborative and engaging stance between them. This was important because it affected the overall training experience by 1) inviting ideas and participation from support workers; and 2) modelling a partnership approach between family carers and support providers.

I was also aware of myself as a passive observer and wondered about the potential impact of my presence on the experience of the training. I usually sat in the corner of the room, silently, taking notes every once in a while. I felt a bit uncomfortable and secluded in the first two training sessions. I noted that the participants were not really

interacting with me, even when I was giving instructions on how to complete the measures.

I reflected on this with my thesis supervisor who asked me to think about my usual position as a trainee clinical psychologist and my current position as a researcher. I realised I came to the research setting with a trainee mindset of engaging people and being appreciated in return. However, this was not necessarily bound to happen in a 30 minute interaction, early in the morning, before a training session. Thus, I was able to adapt my expectations of myself and the participants to the context. I was more aware of my 'position' and what it meant in terms of interactional outcomes.

Secondly, as I watched the training repeatedly, I noticed new concepts, ideas and emotions. It was truly touching to watch the stories of family carers. This helped me know the content of the training well enough to be able to engage participants in the one-to-one interviews. On the other hand, this could have also limited my capacity to explore alternative and unfamiliar views. It also made me think about my choice of measures and in particular, the use of SJTs. My understanding of LWU and the way it could affect participants changed and I realised that my initial approach to the measures chosen might have impeded a more suitable evaluation of the training. For instance, focus groups, rather than quantitative measures, could have potentially uncovered more pertinent outcomes.

The interviews

The idea of conducting interviews was welcomed by everyone involved in the research. Bearing in mind the complexity of SJTs, we hoped to obtain more meaningful

data from personal accounts. I conducted the one-to-one interviews although I had already briefly introduced myself and met the participants during the training sessions. This might have resulted in social desirability bias because the participants knew that I was personally conducting the research, since I administered the measures and attended the training sessions. However, I encouraged them to be as honest as possible because any type of feedback, positive as well as negative, was helpful.

I enjoyed interviewing the participants and felt like I was getting to know them on a more personal level. However, I noticed that the majority of interviewees were White British women (77%) whereas the second highest percentage of training participants' ethnicity was reported to be Black British/ African/ Caribbean at baseline (33.8%). This made me think about my own cultural contributions, as a young Middle Eastern woman, and how they might have affected participants' decision to partake in the one-to-one interview. Unfortunately, this meant that findings gleaned from the interviews may have been biased towards White, female support workers.

Implications and future directions

The use of SJTs was an interesting, albeit difficult, task. The choice of this measure proved to be more complex than I had anticipated. Interviews on the other hand were much more manageable and suited to capture the experience of the training. The choice of quantitative measures needs to be carefully considered in future research as well as their validation on the population being tested.

SJTs appeared more suitable to a certain category of support workers who were younger, had good literacy skills, and were able to deal with pressured academic tasks.

Future research needs to focus on support workers whose responses to the training were not necessarily captured. This could be facilitated by using either simpler measures or qualitative methods. Additionally, men and ethnic minority participants' points of view were underrepresented in the follow-up and/or interviews and will need to be considered in future research.

Finally, ethnographic observations of the training sessions could facilitate a comprehensive assimilation of the dynamics that may affect the training and its impact. These observations coupled with other sources of data gathered could lead to data triangulation, a method that utilises various sources of data to explore an event in numerous contexts (Hodges et al., 2008). This could be particularly important in this kind of evaluation as it allows for a more reflective and comprehensive account of the phenomenon being examined.

Conclusion

Despite the challenges and limitations, conducting this research was an interesting and rewarding experience. My close involvement in the evaluation of the training helped me consider the various strengths and limitations presented by the design and choices made. Future research will need to pay close attention to the views of diverse support workers, by adopting various research methods, in order to present a comprehensive picture of the outcomes of LWU. Presenting the preliminary findings to the different providers and individuals involved in this research will give them an initial indication of the impact of the training on support workers. It will also help the developers of LWU to consider ways to improve the training and draw on its many strengths.

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Appendices

Appendix A: Search strategy on PsycInfo

Search terms

1. intellectual development disorder/
2. intellectual development disorder.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
3. intellectual disabilit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
4. mental retard*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
5. learning disabilit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
6. cognitive disabilit*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
7. 1 or 2 or 3 or 4 or 5 or 6
8. caregivers/
9. (Carer* or caregiver* or caretak*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
10. 8 or 9
11. relationship*.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
12. 7 and 10 and 11
13. (relation* or partner* or participat*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
14. working together.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
15. joint effort.mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]
16. 11 or 13 or 14 or 15
17. 7 and 10 and 16
18. autism spectrum disorders/
19. (Pervasive developmental disorder* or autis* or ASD or autism spectrum disorder*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

20. 7 or 18 or 19

21. exp Collaboration/

22. ("Interpersonal relationship*" or "sensitivity" or "parental involvement" or collaborat* or cooperat*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title, tests & measures]

23. 21 or 22

24. (" Family carer*" or parent* or mother* or father* or sibling* or grandparent*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title]

25. (" Formal carer*" or "service provider*" or staff or professional*).mp. [mp=title, abstract, heading word, table of contents, key concepts, original title]

26. 10 or 24

27. 10 or 25

28. 16 or 23

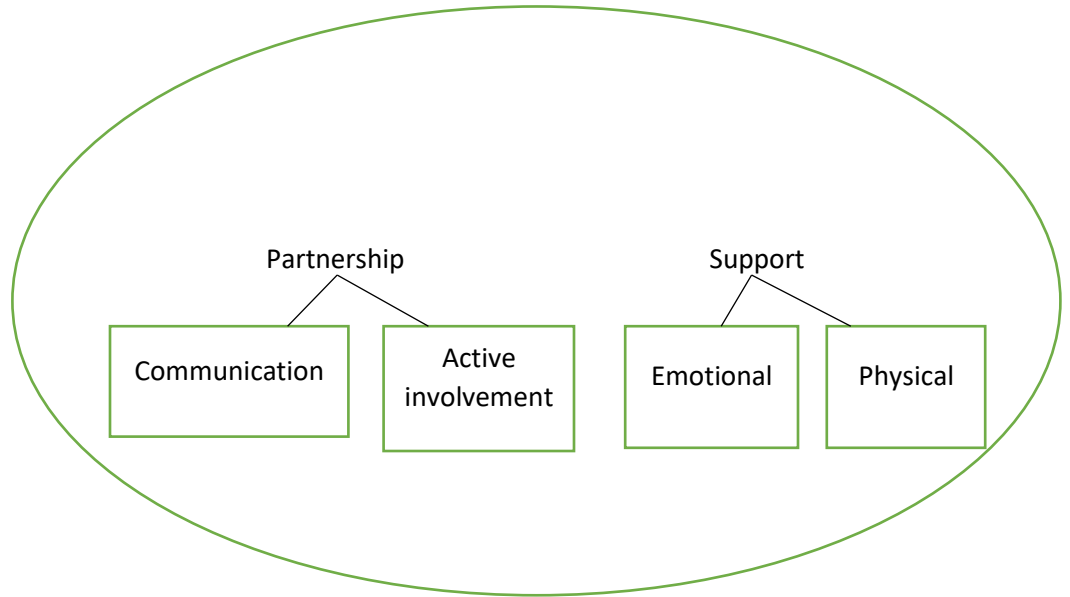
29. 20 and 26 and 27 and 28

**Appendix B: An example of descriptive theme
'conflict' with its subthemes and supporting quotes**

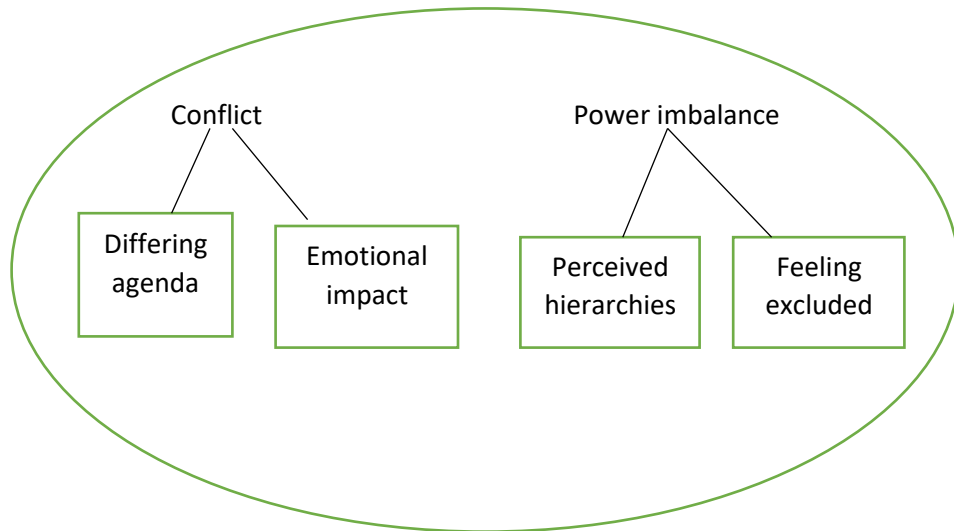
Descriptive theme	Subtheme	Supporting quotes
Conflict	Differing agendas	#1 <i>'[Formal carers] had their ideas about what they wanted to do and I would have to say that they disregarded any input that I would offer or suggest. I took her out.'</i> (Llewellyn et al., 2004, p.389)
		#2 <i>'It was like as if you know you said something and he went totally against it.'</i> (James, 2015, p.42)
	Emotional impact	#1 <i>'Made me very ill. . . . I ended up on medication towards the end of last year for a depressive illness.'</i> (James, 2015, p.47)
		#2 <i>'My partner was fearful and she kept asking the social worker if she would take [relative] off us[...]'</i> . (Lawrence, 2017, p.89)

**Appendix C: Map of synthesis of descriptive themes
into analytical themes**

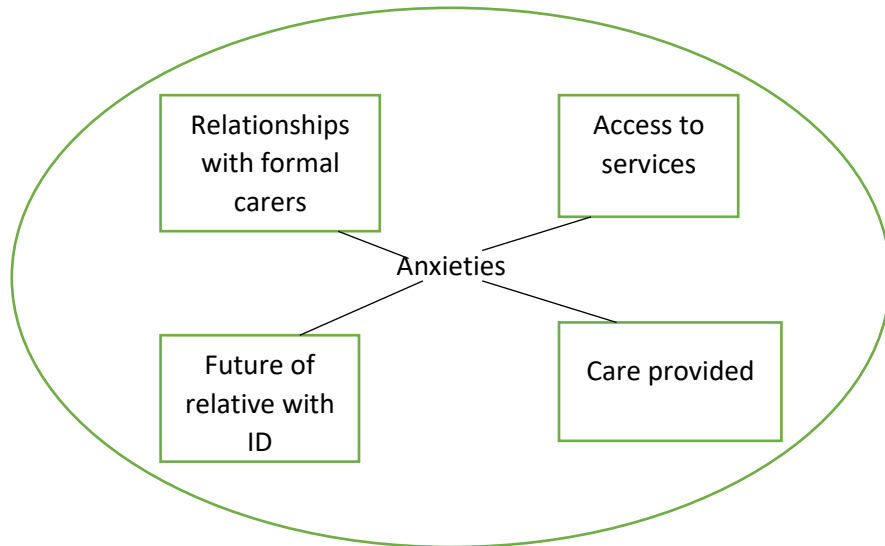
Empowering relationship



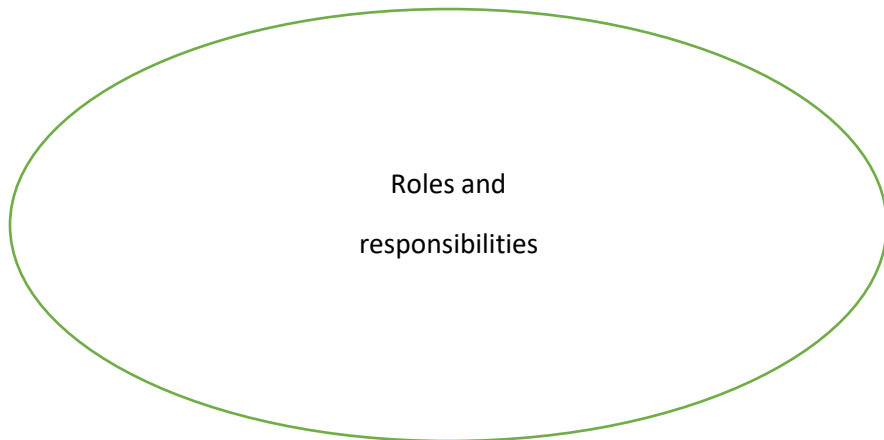
Disempowering relationship



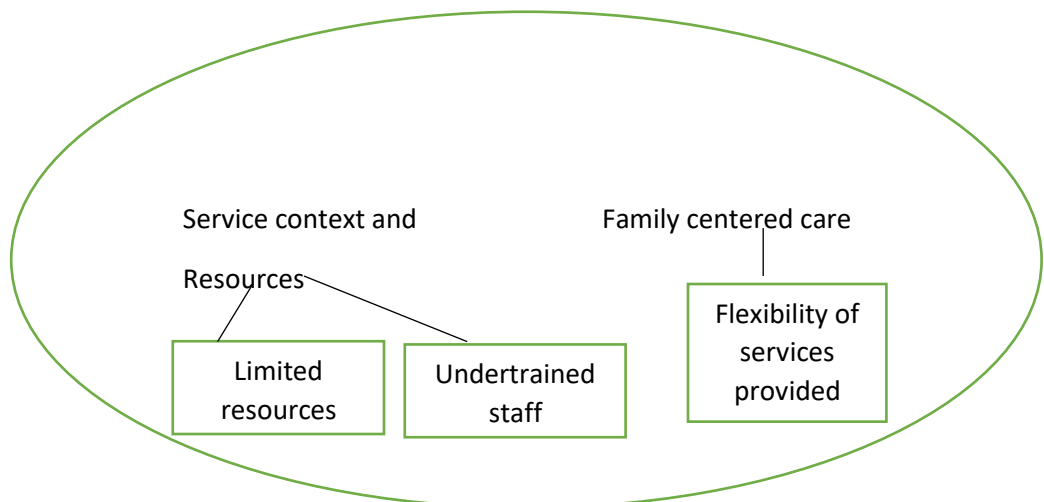
Relationship of dependence



Relationship as an identity



Triadic relationship



**Appendix D: Emails sent to managers and participants
prior to the training**

Briefing notes for participants on “Learn With Us” training workshops 2018.

- We are undertaking a research evaluation of the *Learn With Us* training programme during 2018. Researchers at University College London are working with Islington Social Services, Centre 404 and with family carers.
- The UCL researcher, Nadia Dandan, will ask you to respond to some questions before and after the training session. She will explain the measures and timetable of the day. Please do not hesitate to ask questions if you are unsure about something.
- All your responses on measures including any personal information will remain **confidential** and will only be used for the purpose of our research. Managers and other staff members will not have access to your response or personal information. You have the right to choose what information you want to give us. You can also opt out of the study for any reason and are in no way obliged to participate unwillingly.
- This is in **not** an evaluation of your skills/competencies on the job, rather it is an evaluation of the training itself. Your input is very valuable to us and will help us improve and develop training methods. Therefore, we appreciate your effort and urge you respond honestly and to the best of your knowledge.
- If at any point you feel distressed or material presented makes you uncomfortable, please let the UCL researcher or your manager know. The researcher will be present throughout the training and will be available to you should you need any support.
- Your participation is really valuable to Islington Social Services and to other organisations adopting this training. It can help us build on and refine our training methods. Therefore, we greatly appreciate your honest input and your time.
- We are sending you an example of the Situational Judgement questionnaire, so you can familiarise yourself with the kind of scenario Nadia will be using on the day.

Briefing notes for managers

How can you help?

- Briefly let your staff know that a UCL research student will be collecting data on the outcomes of the training delivered. Explain to them that we are not testing their job performance and that they will be in no way evaluated/judged based on the answers they give. Also, identifiable answers will not be disseminated to other team members or managers.
- Let them know that there will be questionnaires administered before and after the training and should take about 50 minutes in total.
- One of the questionnaires will be timed but staff members are again not being tested on their competencies and should only respond as best they can. The questionnaire might be somewhat stressful due to timing constraints and vignette style scenarios. Staff should inform trainers or researcher if they feel overwhelmed or unable to respond.
- Filling in the questionnaire is part of the training and staff should be encouraged to participate unless they have a valid reason for not doing so. Therefore, please advise them as much as possible to arrive on time and not leave before the end of the training- unless of course they need to.
- Participating in the 3 months follow-up is not mandatory but it will be offered to everyone present at the trainings. Staff who agree to take part will receive cash giveaways (researcher will explain more on the day of the training).
- If for any reason a staff members has concerns or feels distressed, please encourage them to talk to the researcher or their manager so support can be offered to them.

What we hope your staff can help us with.

- Letting us know if they feel distressed or want to talk to someone about an issue related to training or the material administered.
- As much as possible, arriving on time and only leaving after having completed the questionnaires.
- Ask questions if uncertain about something/ be open about any concerns they might have.
- Their participation is really valuable to us and to the centres adopting this training. It can help us build on and refine our training methods. Therefore, we greatly appreciate their honest input and their time.

Appendix E: Sample handouts



THE CHEESE SANDWICH EXERCISE

Scenario:

Jimmy lives in a flat by himself, with support. His parents visit him and ask staff if he has been eating regular meals. Jimmy's support workers explain that he has asked to have a cheese sandwich for his dinner every evening that week.

Jimmy's parents are concerned about this, as they think he should be eating a more varied diet. The member of staff explains that Jimmy chose to have a cheese sandwich each night and that staff have to respect his decision.

Duty of Care:**How the choice is offered:****Best interest:****Work with family:**



--	--

CHEESE SANDWICH EXERCISE: SOME ANSWERS

<p>Scenario:</p> <p>Jimmy lives in a flat by himself, with support. His parents visit him and ask staff if he has been eating regular meals. Jimmy’s support workers explain that he has asked to have a cheese sandwich for his dinner every evening that week.</p> <p>Jimmy’s parents are concerned about this, as they think he should be eating a more varied diet. The member of staff explains that Jimmy chose to have a cheese sandwich each night and that staff have to respect his decision.</p>	
<p>Duty of Care:</p> <p>Give Jimmy choice and control over his decisions</p> <p>He may need help making that choice.</p> <p>Help and encourage him to eat a varied and healthy diet.</p> <p>Look at the reason why Jimmy only wants cheese sandwiches – Dental problems? Language issues?</p> <p>Staff should have noticed this was an issue before family had to point it out.</p>	<p>How the choice is offered:</p> <p>Needs more than ‘yes/no’ closed question – what are the different ways a choice can be offered?</p> <p>Frequently an automatic “no” to unfamiliar things can feel the safest option. Jimmy may need encouragement to try some new options – could lead to tasting session activity.</p> <p>Have appropriate communication tools been used? E.g. picture cards.</p> <p>Is he just eating bread and cheese? Could there be some variety as a starter e.g. a toasted sandwich, add lettuce and tomato</p>

Best interest:	Work with family:
<p>To eat a varied and healthy diet</p> <p>Is Jimmy involved in food shop? Does he have choice over what's being bought?</p> <p>Some people may be unable to make an informed choice due to lack of capacity; someone might have to act in their best interests.</p>	<p>Use the family as a resource – is it common behaviour for Jimmy? Does family have any suggestions for supporting him to eat a more varied diet?</p> <p>Follow up with parents – call/email/leave message in communication book to give update on progress (if parents want this).</p> <p>Invite family round for meal – get Jimmy involved in cooking.</p> <p>Regular contact with family – think about ongoing work to reduce anxieties.</p>



COCA COLA BOTTLE EXERCISE

Some of the stressful events that can take place in the life of a mother who has a daughter with severe learning disabilities, from birth to 25 years

Birth The day after my daughter is born, the doctor tells me, without her father present, she will always have the mental age of a two year old or less. He then leaves before I can ask him any questions.

1 year I have to give up my job to look after her. My partner and I go into debt.

2 years When she is two years old I am offered some help: two mornings a week at the other end of the borough with 2 bus rides to get there.

4-5 years She is offered a place at the local special school. I am sure it is not right for her, they tell me it is and that's all there is on offer. I gatecrash an education committee and start shouting at them. I fight for a year to get her into a school in another borough, with help from my local councilor and MP.

8 years My relationship with her father breaks down and he leaves. He looks after her every other weekend; otherwise I am a single parent. I am given anti-depressants.

13 years My daughter's epilepsy gets worse with the onset of puberty. Her medication is changed without consultation. When I say it's making her agitated and ill, I am not listened to.

16 years A new therapist at the school says my daughter is at risk of choking and all her food must be pureed, despite the pleasure she gets from food and that she has never choked. I am not listened to until our consultant neurologist supports what I am saying.

19 years My daughter is due to leave school in the summer, and the transition plan is for her to go to a specialist college I have found in another borough. A month before the end of term I am told she cannot go there.

20 years I am exhausted as my daughter is not sleeping well and I have dangerously high blood pressure. I am too tired to cook healthy food, relying on ready meals and chocolate. My weight gain really upsets me.

23 years They've told me there's a place coming up in supported housing. I know I can't go on looking after her but I feel so guilty.

Appendix F: Booklet of measures

Information Sheet for Participants in Research Studies

Title of Project: **Evaluation of the Learn with Us training**

Investigators: Nadia Dandan and Katrina Scior
Research Dept of Clinical Educational & Health Psychology
University College London, Gower Street
London WC1E 6BT
United Kingdom
+44 (0)20 7679 1897

Centre 404 is pleased to be working with University College London's Clinical Psychology Dept to carry out a research evaluation of the "Learn With Us" training workshop. You have been invited to participate in this study as a support worker who is attending the 'Learn With Us' training.

As part of this study, you will be invited to complete a short survey which includes a brief questionnaire and six short scenarios – for each you will be asked to rank the given responses in terms of how appropriate you think they are. Completion of the questionnaire will take approximately 15 minutes. Immediately after the training, you will be asked to complete the same questionnaire again. You will also be asked at that point whether you are willing to complete the questionnaire again in three months' time and will have the choice to be entered into a prize draw for a £50 Amazon voucher. Additionally, if you agree to be contacted for a 20 minute one to one interview in three months' time, you will receive £10 cash for your contribution.

You have the right to opt out of the study at any time during the training should you wish to do so. You also have the right not to complete demographic questions and to decline questions that you may find overly challenging.

This study has been approved by the Ethics Chair of the Research Department of Clinical Educational & Health Psychology [Project ID No: CEHP/2016/551].

All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only the UCL researchers detailed above will have access to the data.

Please retain this sheet for your personal use if you wish

Evaluation of the 'Learn With Us' Training



Your Initials:.....

Please return this booklet to the researcher once you have completed it.

To be completed by researcher

Date:..... Group Code:.....

Informed Consent Form

(This form is to be completed independently by the participant after reading the Information Sheet and/or having listened to an explanation about the research.)

Title of Project: **Evaluation of the Learn with Us training**

This study has been approved by the Ethics Chair of the Research Department of Clinical Educational & Health Psychology
[Project ID No: CEHP/2016/551]

Participant's Statement

By ticking this box, I confirm that I have

- read the information sheet;
- had the opportunity to ask questions and discuss the study;
- been given contact details should I wish to ask questions or have concerns about the study;
- am happy to take part in the study.
- I am aged 18 years or over (for ethical reasons we cannot recruit anyone below the age of 18)

I understand that I am free to withdraw from the study without penalty if I so wish. I understand that I consent to the processing of my personal information for the purposes of this study only. I understand that any such information will be treated as strictly confidential subject to legal constraints and professional guidelines handled in accordance with the provisions of the Data Protection Act 1998.

Please turn to back of this page →

Part I

Brief information about you:

Female/Male	Age:
<p>Ethnicity:</p> <p>White British or Other <input type="checkbox"/></p> <p>Black British/ African/ Caribbean <input type="checkbox"/></p> <p>Asian <input type="checkbox"/></p> <p>Middle Eastern <input type="checkbox"/></p> <p>Other, please specify</p>	
<p>Work experience:</p> <p>How long have you worked as a support worker for people with learning disabilities.</p> <p>Less than a month <input type="checkbox"/></p> <p>Less than a year <input type="checkbox"/></p> <p>1-2 years <input type="checkbox"/></p> <p>3-4 years <input type="checkbox"/></p> <p>5 years or more <input type="checkbox"/></p>	
<p>During the past month, how often have you had contact with service users' family members (whether in person, by phone, or otherwise)? Please circle the appropriate answer below</p> <p>Not at all Once or twice A few times At least 1x a week (Almost) Every day</p>	

Please turn to back of this page —>

During the past month, how often have you and/or your staff team had any disagreements or differences of opinion with family members over the following issues? Please **circle** the appropriate number.

	Not at all	Once or twice	A few times	At least 1x a week	(Almost) Every day
a. Personal care (bathing, dressing, toileting)	0	1	2	3	4
b. Meals/food/nutrition	0	1	2	3	4
c. Medication and/or Health related issues	0	1	2	3	4
d. Activities programme	0	1	2	3	4
e. Communication with families	0	1	2	3	4
f. Quality of support and care	0	1	2	3	4
g. Responsiveness to service users' needs and wishes	0	1	2	3	4
h. Other, please specify_____	0	1	2	3	4

Please turn to back of this page →

Directions: Indicate the extent to which you agree with the following statements using this scale:

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat

- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

1. I can relate to the everyday problems faced by family carers of people with a learning disability/autism and challenging behaviour.
2. I can readily see things from the point of view of family carers of people with a learning disability/autism and challenging behaviour.
3. I can imagine what it might be like to have a child with a learning disability/autism and challenging behaviour.
4. I can understand why a family carer of a person with a learning disability/autism might want to be involved in the care of their child, even after they have left home.

1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6
1	2	3	4	5	6

Please turn to back of this page →

Situational judgements

In the following you will be presented with six scenarios, and five possible responses for each.

- For each scenario please **rank the five responses presented in order of appropriateness**, i.e. how you think staff should respond in the situation (1 = most appropriate; 5 = least appropriate). NB: Please rank all five responses and do not use the same rank more than once.
- Please write your final ranking in the box next to each response. So for example, if you see B as the most appropriate response, put a 1 in the box next to it, a 2 in the box next to the second best response (D in this example) and so on. Remember to assign ranks to all other responses, e.g.

Response A	3
Response B	1
Response C	4
Response D	2
Response E	5

- You will have approximately 15 minutes in total so please work quickly and attempt all the questions.
- You may sometimes feel that you would like more information before answering. However, please give your best answer based on the information provided.

Please turn to back of this page →

1. Dave is 28, and lives in his own flat with low level support. He has gone into a mobile phone shop and bought a new phone on an expensive contract. He already has a smartphone on contract which works well. He shows the phone to support staff and asks them not to tell his parents as they will be cross with him. They will want to know how he is going to pay his bills in the coming months with the new contract draining his bank account. Staff are in a dilemma about how to handle this as it has happened several times before and they are concerned that the parents might blame them for not preventing it.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Respect Dave's wishes and let him keep the phone and not tell his parents. This means that sooner or later the direct debit for his utility bills will not be paid, but this is part of Dave learning about managing money.	
B. Tell Dave that they won't tell his parents but insist that they take it back to the shop together. Explain that he has learning disabilities and try to return the phone and cancel the contract. They know Dave will be very upset by this course of action.	
C. Respect Dave's desire to keep the phone but tell him that you will have to inform his parents because of the financial implications.	
D. Point out that sooner or later his parents will see the phone anyway so it is better to tell them now.	
E. Tell Dave that as this sort of situation has happened several times before, you will have to ask for a meeting with professionals, family and Dave, to discuss if he is able to manage his money himself.	

Please turn to back of this page →

2. John is a 25 year old man who lives in a flat close to his mother, Margaret. Margaret is really happy with her son's new support staff. John has had problems with his feet since childhood and needs to wear 'good shoes that provide support', so that he doesn't get pains in his feet which then further affects his mobility. He has needed some new shoes for a while and he really likes the fashionable trainers of Gary, his favourite support worker. Gary and John went out shopping and John chose a pair of trainers the same as Gary's. Unfortunately, these were too narrow for John's feet and caused him pain when walking and ended up being given to the charity shop. Gary had gone with John to spend his money without prior discussion with his mother.

Rank in order the following alternative actions that the support worker could have taken before going shopping:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Gary tells John that he cannot have those trainers because they will be bad for his feet, and encourages him to make another choice.	
B. Gary decides to contact Margaret for advice without telling John, because John has set his heart on having the same trainers as him.	
C. Gary suggests to John that they invite Margaret to come shopping for shoes with them.	
D. Gary says to John that John must talk to his mother, Margaret, before going shopping for shoes.	
E. Gary decides not to tell Margaret because he thinks that it is important for John to learn from experience rather than being told what to do.	

Please turn to back of this page →

3. Mary is a woman in her mid-20s with mild learning disabilities who has been living successfully in her new home for the past two months. She has good relationships with her support workers who are encouraging her to develop her self-esteem and confidence. Mary would like a new shorter hair style; like one she has seen in a magazine. The support worker asks if she would like to speak to her mother first. Mary says she would like it to be a nice surprise for her mother. When Mary's mother sees her new hairstyle, she is angry. She tells the support worker that she doesn't like the haircut and that she has always taken Mary to the hairdresser.

Rank in order how the staff team as a whole should respond:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Apologise to Mary's mother and assure her that next time Mary is having a haircut she will be contacted to ask if she will want to go too.	
B. Explain to Mary's mother that it is appropriate for her as a young woman in her 20s to make her own decision about her hairstyle.	
C. Discuss with your manager whether it is possible to acknowledge with Mary's mother how big a life change this time is for her as well as for Mary.	
D. Discuss with your manager whether there needs to be a meeting with Mary and her mother to discuss her ability to make everyday decisions.	
E. Arrange to speak to Mary's mother to discuss how she would have liked the staff to deal with this situation in the light of them trying to develop Mary's independence.	

Please turn to back of this page →

4. Janet is a woman in her mid-thirties with a severe learning disability and autism with frequent challenging behaviour. Her support workers find it hard to motivate her to do anything; even getting up in the morning or leaving her room. She is reluctant to do any activities and can be quite resistant when such demands are made of her. However, she loves biscuits, and the staff find that if she knows she will get a biscuit at the end of an activity, she can be persuaded to go out and to take part in activities. Her parents are very concerned that she is eating too many biscuits, that she is putting on weight and that she is more likely to need dental treatment (which requires a general anaesthetic). The parents argue that there should be other ways of motivating their daughter to be active and engaged.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Parents and staff jointly discuss if there were alternative incentives that were successful at home, or some different incentives that they could try out.	
B. Staff agree to stop the biscuits for a trial period. However, they explain to the parents that they are sure that it will lead to challenging behaviour. They agree to record any incidents over a week and to keep the parents informed.	
C. Continue with the biscuits but suggest a healthy eating programme to offset the weight gain.	
D. Explore the option of healthier biscuits and hope Janet won't notice the difference.	
E. Continue with the biscuits strategy out of respect for Janet's choice. Biscuits enable her to go out and get involved in activities, which is in her best interest.	

Please turn to back of this page →

5. Ali, a 19-year-old man with moderate learning disabilities, moved into a supported living flat six months ago. He gets on very well with his flat mate John. His very supportive family explained to the staff what was important to them as Muslims and how Ali could be supported, including around what he eats and going to the mosque. This information was written down as part of Ali's support plan. However, since moving Ali has shown a liking for bacon sandwiches, because John whom he lives with has them every weekend.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. The staff allow Ali to eat a bacon sandwich if he asks for one when John has his. The staff consider Ali has the capacity to make this choice.	
B. Ali, his parents and a trusted staff member sit down together to talk about why bacon is not permitted on religious grounds and try to persuade him to have something different instead.	
C. The service convenes a best interest meeting, including the parents, the manager of the service, the social worker, with advice obtained from the Imam from the local mosque.	
D. The staff tell Ali that he cannot have a bacon sandwich because his family won't allow it.	
E. Try to persuade John only to have bacon sandwiches when Ali is not around.	

Please turn to back of this page →

6. Miray, 35, has profound learning and physical disabilities; she lives at home with her family and spends regular weekends at a respite centre. Miray needs one to one support in all aspects of her life including at meal times. During her latest stay Miray had a coughing fit while she was being fed on the first evening. As a precaution and for the rest of her stay, the respite service decided that it was best if her food was pureed to minimise risk of choking. When the staff informed the parents they disagreed that this course of action was necessary, because at home she has never shown any signs of choking even if she has been coughing. The parents explain that eating and tasting the different textures of food has always given Miray a lot of pleasure. However, some of the staff who recently attended a course on choking risks are still worried that there is a serious risk to Miray's health if they do not blend her food.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Ask the parents if they would be willing to come to a meeting at the respite centre together with the speech and language therapist to discuss the best course of action.	
B. The staff informs the parents that they are going to continue to puree Miray's food until there has been assessment and advice from the speech and language therapist.	
C. The service continues to puree Miray's food without telling the parents.	
D. The manager asks the speech and language therapist if, with the parents' consent, they can make a joint home visit to observe how the parents manage meal times with their daughter.	
E. The staff are willing to accept the parents' view and decide not to puree Miray's food until there has been assessment and advice received from the speech and language therapist.	

END of Part I (please return the completed form to the researcher)

Part II

Your initials:.....

Directions: Indicate the extent to which you agree with the following statements using this scale:

- 1 = Disagree strongly
- 2 = Disagree moderately
- 3 = Disagree somewhat

- 4 = Agree somewhat
- 5 = Agree moderately
- 6 = Agree strongly

1. I can relate to the everyday problems faced by family carers of people with a learning disability/autism and challenging behaviour.	1	2	3	4	5	6
2. I can readily see things from the point of view of family carers of people with a learning disability/autism and challenging behaviour.	1	2	3	4	5	6
3. I can imagine what it might be like to have a child with a learning disability/autism and challenging behaviour.	1	2	3	4	5	6
4. I can understand why a family carer of a person with a learning disability/autism might want to be involved in the care of their child, even after they have left home.	1	2	3	4	5	6

Please turn to back of this page →

Situational judgements

In the following you will be presented with six scenarios, and five possible responses for each.

- For each scenario please **rank the five responses presented in order of appropriateness**, i.e. what you think how staff should respond in the situation (1 = most appropriate; 5 = least appropriate). NB: Please rank all five responses and do not use the same rank more than once.
- Please write your final ranking in the box next to each response. So for example, if you see B as the most appropriate response, put a 1 in the box next to it, a 2 in the box next to the second best response (D in this example) and so on. Remember to assign ranks to all other responses, e.g.

Response A	3
Response B	1
Response C	4
Response D	2
Response E	5

- You will have approximately 15 minutes in total so please work quickly and attempt all the questions.
- You may sometimes feel that you would like more information before answering. However, please give your best answer based on the information provided.

Please turn to back of this page →

1. John is a 25 year old man who lives in a flat close to his mother, Margaret. Margaret is really happy with her son's new support staff. John has had problems with his feet since childhood and needs to wear 'good shoes that provide support', so that he doesn't get pains in his feet which then further affects his mobility. He has needed some new shoes for a while and he really likes the fashionable trainers of Gary, his favourite support worker. Gary and John went out shopping and John chose a pair of trainers the same as Gary's. Unfortunately, these were too narrow for John's feet and caused him pain when walking and ended up being given to the charity shop. Gary had gone with John to spend his money without prior discussion with his mother.

Rank in order the following alternative actions that the support worker could have taken before going shopping:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Gary tells John that he cannot have those trainers because they will be bad for his feet, and encourages him to make another choice.	
B. Gary decides to contact Margaret for advice without telling John, because John has set his heart on having the same trainers as him.	
C. Gary suggests to John that they invite Margaret to come shopping for shoes with them.	
D. Gary says to John that John must talk to his mother, Margaret, before going shopping for shoes.	
E. Gary decides not to tell Margaret because he thinks that it is important for John to learn from experience rather than being told what to do.	

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Dave is 28, and lives in his own flat with low level support. He has gone into a mobile phone shop and bought a new phone on an expensive contract. He already has a smartphone on contract which works well. He shows the phone to support staff and asks them not to tell his parents as they will be cross with him. They will want to know how he is going to pay his bills in the coming months with the new contract draining his bank account. Staff are in a dilemma about how to handle this as it has happened several times before and they are concerned that the parents might blame them for not preventing it.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Respect Dave's wishes and let him keep the phone and not tell his parents. This means that sooner or later the direct debit for his utility bills will not be paid, but this is part of Dave learning about managing money.	
B. Tell Dave that they won't tell his parents but insist that they take it back to the shop together. Explain that he has learning disabilities and try to return the phone and cancel the contract. They know Dave will be very upset by this course of action.	
C. Respect Dave's desire to keep the phone but tell him that you will have to inform his parents because of the financial implications.	
D. Point out that sooner or later his parents will see the phone anyway so it is better to tell them now.	
E. Tell Dave that as this sort of situation has happened several times before, you will have to ask for a meeting with professionals, family and Dave, to discuss if he is able to manage his money himself.	

Please turn to back of this page →

2. Ali, a 19-year-old man with moderate learning disabilities, moved into a supported living flat six months ago. He gets on very well with his flat mate John. His very supportive family explained to the staff what was important to them as Muslims and how Ali could be supported, including around what he eats and going to the mosque. This information was written down as part of Ali's support plan. However, since moving Ali has shown a liking for bacon sandwiches, because John whom he lives with has them every weekend.

Rank in order how the staff team as a whole should respond:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. The staff allow Ali to eat a bacon sandwich if he asks for one when John has his. The staff consider Ali has the capacity to make this choice.	
B. Ali, his parents and a trusted staff member sit down together to talk about why bacon is not permitted on religious grounds and try to persuade him to have something different instead.	
C. The service convenes a best interest meeting, including the parents, the manager of the service, the social worker, with advice obtained from the Imam from the local mosque.	
D. The staff tell Ali that he cannot have a bacon sandwich because his family won't allow it.	
E. Try to persuade John only to have bacon sandwiches when Ali is not around.	

Please turn to back of this page →

3. Miray, 35, has profound learning and physical disabilities; she lives at home with her family and spends regular weekends at a respite centre. Miray needs one to one support in all aspects of her life including at meal times. During her latest stay Miray had a coughing fit while she was being fed on the first evening. As a precaution and for the rest of her stay, the respite service decided that it was best if her food was pureed to minimise risk of choking. When the staff informed the parents they disagreed that this course of action was necessary, because at home she has never shown any signs of choking even if she has been coughing. The parents explain that eating and tasting the different textures of food has always given Miray a lot of pleasure. However, some of the staff who recently attended a course on choking risks are still worried that there is a serious risk to Miray's health if they do not blend her food.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Ask the parents if they would be willing to come to a meeting at the respite centre together with the speech and language therapist to discuss the best course of action.	
B. The staff informs the parents that they are going to continue to puree Miray's food until there has been assessment and advice from the speech and language therapist.	
C. The service continues to puree Miray's food without telling the parents.	
D. The manager asks the speech and language therapist if, with the parents' consent, they can make a joint home visit to observe how the parents manage meal times with their daughter.	
E. The staff are willing to accept the parents' view and decide not to puree Miray's food until there has been assessment and advice received from the speech and language therapist.	

Please turn to back of this page →

4. Mary is a woman in her mid-20s with mild learning disabilities who has been living successfully in her new home for the past two months. She has good relationships with her support workers who are encouraging her to develop her self-esteem and confidence. Mary would like a new shorter hair style; like one she has seen in a magazine. The support worker asks if she would like to speak to her mother first. Mary says she would like it to be a nice surprise for her mother. When Mary's mother sees her new hairstyle, she is angry. She tells the support worker that she doesn't like the haircut and that she has always taken Mary to the hairdresser.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Apologise to Mary's mother and assure her that next time Mary is having a haircut she will be contacted to ask if she will want to go too.	
B. Explain to Mary's mother that it is appropriate for her as a young woman in her 20s to make her own decision about her hairstyle.	
C. Discuss with your manager whether it is possible to acknowledge with Mary's mother how big a life change this time is for her as well as for Mary.	
D. Discuss with your manager whether there needs to be a meeting with Mary and her mother to discuss her ability to make everyday decisions.	
E. Arrange to speak to Mary's mother to discuss how she would have liked the staff to deal with this situation in the light of them trying to develop Mary's independence.	

Please turn to back of this page →

5. Janet is a woman in her mid-thirties with a severe learning disability and autism with frequent challenging behaviour. Her support workers find it hard to motivate her to do anything; even getting up in the morning or leaving her room. She is reluctant to do any activities and can be quite resistant when such demands are made of her. However, she loves biscuits, and the staff find that if she knows she will get a biscuit at the end of an activity, she can be persuaded to go out and to take part in activities. Her parents are very concerned that she is eating too many biscuits, that she is putting on weight and that she is more likely to need dental treatment (which requires a general anaesthetic). The parents argue that there should be other ways of motivating their daughter to be active and engaged.

Rank in order the following actions in response to this situation:

Please rank the 5 responses from **most** appropriate (=1) to **least** appropriate (=5)

	Rank
A. Parents and staff jointly discuss if there were alternative incentives that were successful at home, or some different incentives that they could try out.	
B. Staff agree to stop the biscuits for a trial period. However, they explain to the parents that they are sure that it will lead to challenging behaviour. They agree to record any incidents over a week and to keep the parents informed.	
C. Continue with the biscuits but suggest a healthy eating programme to offset the weight gain.	
D. Explore the option of healthier biscuits and hope Janet won't notice the difference.	
E. Continue with the biscuits strategy out of respect for Janet's choice. Biscuits enable her to go out and get involved in activities, which is in her best interest.	

Please turn to back of this page →

Complete the section below if you are happy to participate in a follow-up to this evaluation, to help us understand the impact of Learn with Us better.

Contact details

Please tick one of the boxes below:

- I am happy to be contacted with a view to completing a brief follow-up **questionnaire** (with a chance to enter a draw to win a £50 Amazon voucher)
- I am happy to be contacted again with a view to participating in a **one-to-one interview** about the training and its impact (receive a £10 cash reward).
- I am happy to be contacted about **both** a follow-up questionnaire and interview (both can be completed on the same occasion) (receive a £10 cash reward and a chance to enter a draw for a £50 Amazon voucher)

Full name:

Preferred means of contact (email or phone number):

Alternative means of contact (email or phone number):

Work location:

This information will only be used to contact you for the purposes of our follow up project. The only people with access to your personal information are the UCL research team involved in this particular project. Please speak to the researcher if you have any concerns.

Thank you for participating in this evaluation. If you have any questions please do not hesitate to ask the researcher. Please return this form to the researcher and make sure your initials are on this form.

Appendix G: Interview schedule

Introduction

I want to thank you for taking the time to meet with me today.

My name is Nadia and I would like to talk to you about your experiences participating in the 'Learn with us' training workshop. Specifically, as one of the components of our overall program evaluation we are assessing program effectiveness in order to capture your experience of the training as well as lessons that can be used in future work.

The interview should take about 20 minutes. I will be taping the session because I don't want to miss any of your comments. Although I will be taking some notes during the session, I can't possibly write fast enough to get it all down. Because we're on tape, please be sure to speak up so that we don't miss your comments. All responses will be kept confidential. This means that your interview responses will only be shared with research team members and we will ensure that any information we include in our report does not identify you as the respondent. Remember, you don't have to talk about anything you don't want to and you may end the interview at any time.

Are there any questions about what I have just explained?

Are you willing to participate in this interview?

Interviewee	Researcher	Date
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Aim: Get a more in depth knowledge on how support workers experienced the training.

Q: What did you make of the training you received?

Prompts: Did you learn anything new? Can you give an example?

Did you find it helpful?

What was your experience of having a family carer as a co-facilitator?

Aim: Understand relationship developments amongst support workers and with family carers.

Q: How has this training changed your work relations?

Prompts: How were they before?

With other staff?

With family carers?

Aim: Assess whether training has changed their perception of challenging situations

Q: Can you describe an actual situation/encounter you have been involved in which had required you to take action/make a decision immediately?

Prompts: Who was involved?

If carers were involved in any way, how did you experience the communication with family carers?

If not, why weren't they involved?

Now that you are reflecting on it, what can you say about that same situation?

Aim: Exploring Support workers' understanding of family carers' anxieties about the future of their children

Q: What do you think might be some of the major concerns that family carers have in relation to the future of their son/daughter?

Prompts: What was your understanding of Jo's poem?

Q: Is there anything else you would like to tell me either about your participation in the filmed based training, or about your interaction with family carers?

Appendix H: Sample transcript

Transcript: 180810_002

Researcher: So, what did you make of the LWU training that you received

P7: It was good it showed me a lot things, like how to work with families and how if there is any discord between the family and the management and all that you know how to step in even if the manager is not there, you know how to speak to the family to calm them down. You know sometimes if you don't know how to speak to the family you know it escalates. But if you are able to speak to the family and say 'okay I'm sorry, I will let my manager know when she comes in' just to calm the environment down.

Researcher: And do you think the training helped with that?

P7: It helped a lot because I haven't done this type of training before. So since I've done it now, I know how to speak to the family I know that it helps me more.

Researcher: Did you notice a change in how you communicate with family carers?

P7: Yeah I noticed a change in the way I communicate because it's not easy for them to live... look after that kind of...you know but we don't want to raise fire because we are already under stress, so you know, I speak to a lot of them and they say 'oh I'm so tired' 'oh I just want to go away but it's difficult' they want that break but they find it difficult. Like one of our customers said 'oh my daughter was supposed to go to respite last month but she didn't go because I just wanted to have a'... you understand? So I felt like if I took her it would be helpful for her.

Researcher: How do you deal with that when they say they are tired?

P7: Yeah I just encouraged her and said to her 'it's a good thing when you are tired sometimes you just need the break you just have to say okay I'm going to do this. Even if it's only two days, at least it will give you that break to relax', so it can give her time to go to the gym, to see friends

Researcher: So for you do you think there was a change from before the training to after the training in terms of how you see the communication and interaction?

P7: Hmm, in terms of families that have a disabled child, it changed. Since the training you know you've got to listen to them, you don't have to say 'oh no' you just got to listen to them complain and see how you can deal with it

Researcher: And listening was a big part of the training, do you think this is something that you have learned from the training specifically?

P7: Yes yes, I've learned from the training, although I do listen to them I give them attention so even if it's a busy situation I say 'oh sorry just wait I have an emergency then I'll come back to you' don't just walk away. You know you feel that you don't want to go there...

Researcher: Interact with them...

P7: Yea yea, and where I was working before there was one of our customers, she lost a daughter, when I saw her, because I was on holiday, I say 'oh I'm so sorry for your loss' and all that. So, I didn't even know the other person but I said 'oh I'm so sorry to hear that, I came back from holiday this is what I heard I am really sorry to hear that' you notice that...

Researcher: Did she appreciate it?

P7: Yeah she appreciated so she hugged me and I hugged her, it was tears I said 'oh I'm so sorry do you want a cup of tea?' and I sat her down so she said 'yes please' and we were just chatting for about 10 minutes. After 10 minutes I left her. After this, she saw my manager and she said 'so you know I've seen all of your staff but they just said 'hello', you know they didn't really sympathise for her loss so she said 'oh its only [participant's name]' and I said 'me?' me I didn't know I was doing anything, things like that. So yeah so many ways to calm the costumer down and so on. But we just have to, I think the whole team we just have to give them time, even if the time is not there, you let them know that you will come back to them, don't just say no to them, they hate it, they hate it.

Researcher: [laughs] that was a big part of the training scenarios as well

P7: A big part of the training yeah, as soon as they give them just little attention, yeah they know 'oh no don't worry, it's a busy place, okay don't worry I'm here I'm waiting', you understand? Things like that. The training was very helpful

Researcher: It sounds like its grounded some of your ideas that were already there

P7: Yea yea they were already there. But since I've had the training it added to my knowledge and to the skills as well. Hmmm

Researcher: Okay, hmm and would you say you learned anything new like something that you didn't really know about?

P7: Hmm you know there were a few case studies, I think I can't remember now, I think when somebody was complaining...

Researcher: Was it the video clips?

P7: Yes the video clips. There were a few things that were wrong a few things that were right, you know, how we the support worker, how we can deal with situations like that, how you can get the outcome of it so that you won't flag up. There are some situations maybe the family is not really happy and it's so bad, you understand? That how you speak to them it can calm them down... if not they take it up, I know that yeah.

Appendix I: Sample coding

Code 1: 'Family carers as experts'

[<Files\\P2 180706_002 Transcript>](#) - § 1 reference coded [1.98% Coverage]

Reference 1 - 1.98% Coverage

because I'm not with them for many hours in a day, I'm only for a short period of time, those people, their carers and families are critical for me to help know what's okay, what's not okay, and what kind of change, how should I introduce change, how should I, you know, we want to go to q garden, what are things that I should be aware of, so they are vital, and communication, and knowing these things ya.

[<Files\\P5 180725_002 transcript>](#) - § 2 references coded [2.76% Coverage]

Reference 1 - 1.53% Coverage

Yeah, I mean, yeah, it is good speak to carers in that sort of environment, because, just so that everyone knows what they stands in those things, cause obviously like, I'm not gonna care in the same way they care, so, it's nice to have that honest discussion about things.

Reference 2 - 1.23% Coverage

Ya, it does need to be that way around. And I think the carer should be leading kind of rather, not necessarily cause they are gonna be right but just out of respect for where they are, in the whole chain of relations.

[<Files\\P8 181019_001 transcript>](#) - § 1 reference coded [2.38% Coverage]

Reference 1 - 2.38% Coverage

Yeah, I know, definitely it highlights how important and valuable family are, whether it is like for support or information, or I mean if you are not sure about, especially, some of the service users cannot communicate easily, it is always amazing to have a good kind of circle of support for them that you can go to, to find out from people that know them best, definitely it highlights the importance of that and maybe to know that the service user does rely on certain people and things like that

[<Files\\P9 190118_001 Transcript>](#) - § 2 references coded [5.43% Coverage]

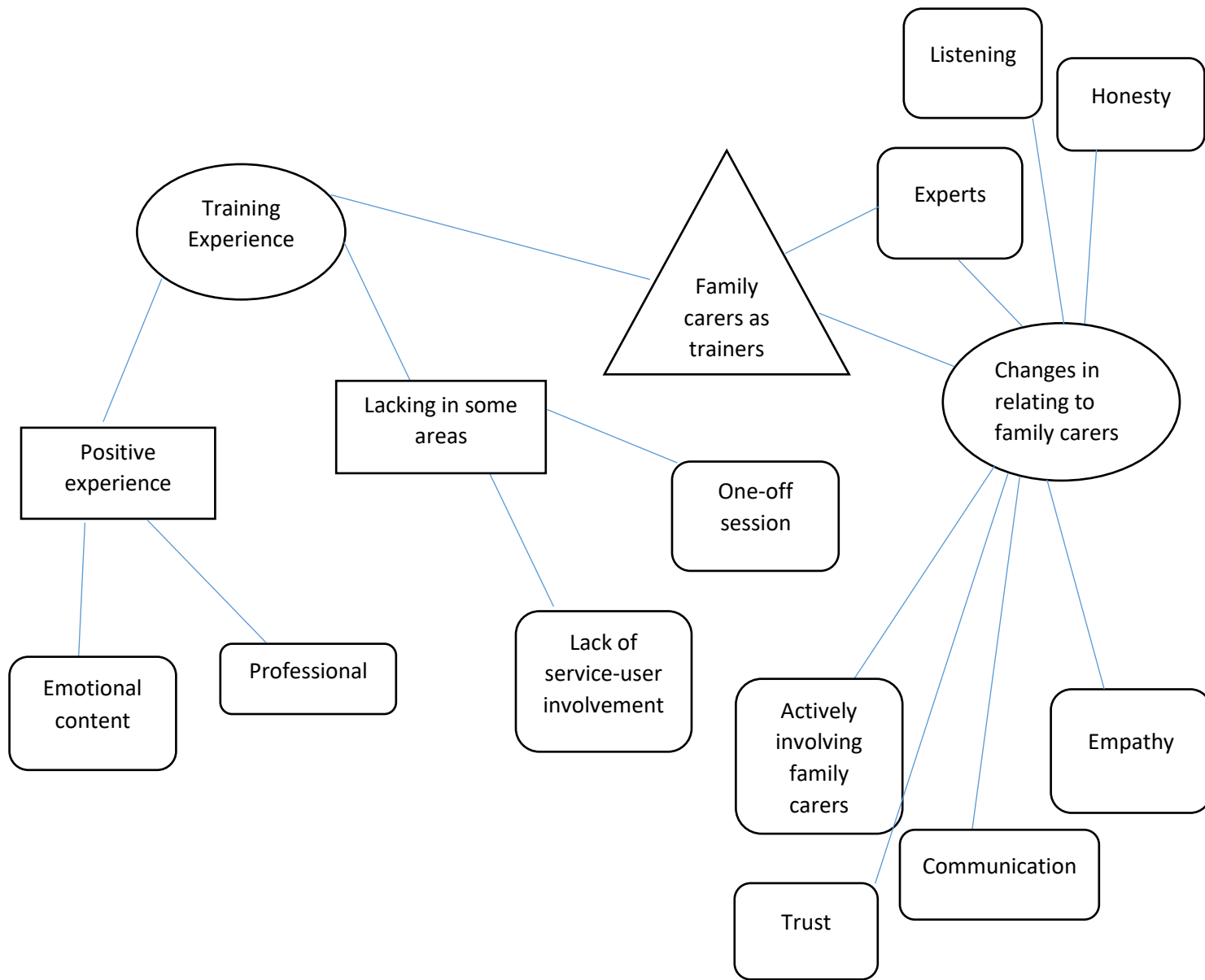
Reference 1 - 3.07% Coverage

Yeah so definitely I would encourage both service-users and my fellow colleagues to kind of you know, bear the family's perspectives in mind and try to get in touch with the family, when you know we are dealing with a situation where we are not quite sure how to do things, where we are faced with a dilemma. So definitely would advise somebody to kind of try to reach out to the family and seek their advice on certain situations

Reference 2 - 2.36% Coverage

So the fact that the family is confident, trusts the abilities of the support workers to deal with an emergency situation that involves their child and vice versa the care team feels that the family, you know because they dealt with it in the past, know how to deal with things so we as support workers would follow their guidance

Appendix J: Sample initial thematic map



Appendix K: Ethics approval emails

From: King, John

Sent: Wednesday, October 17, 2018 9:21 AM

To: Dandan, Nadia; Scior, Katrina; VPRO.Ethics

Subject: Re: Amendment form- Research

Dear Nadia and Katrina,

I'm happy to approve this amendment. I am copying in the REC and attached the form here as a record of the approval.

Best wishes,

John

From: King, John

Sent: Tuesday, November 21, 2017 9:48 AM

To: Scior, Katrina Cc: Dandan, Nadia

Subject: Re: request for approval of an ethics amendment

Many thanks Katrina. I'm happy to approve this as an amendment to your ethics. I've attached it to this email and copied in the REC for their records.

John

Appendix L: Informed consent

Title of Project: **Evaluation of the Learn with Us training**

Investigators: Nadia Dandan and Katrina Scior
Research Dept of Clinical Educational & Health Psychology
University College London, Gower Street
London WC1E 6BT
United Kingdom
+44 (0)20 7679 1897

Centre 404 is pleased to be working with University College London's Clinical Psychology Dept to carry out a research evaluation of the "Learn With Us" training workshop. You have been invited to participate in this study as a support worker who attended the 'Learn With Us' training.

During the interview, you will be asked about your experiences participating in the 'Learn with us' training workshop. Specifically, as one of the components of our overall program evaluation we are assessing program effectiveness in order to capture your experience of the training as well as lessons that can be used in future work. The interview should take about 20 minutes and I will be taping the session. At the end of the interview you will receive a 10 Amazon egift voucher to thank you for your participation.

Informed consent

Your participation in this study is voluntary. All information you offer is voluntary. You have the right to withdraw at any point during the interview, for any reason and without and prejudice.

By signing below, you acknowledge that your participation is voluntary, that you are above the age of 18 and that you are aware that you may terminate your participation at any point and for any reason.

All data will be handled according to the Data Protection Act 1998 and will be kept anonymous. Only the UCL researchers detailed above will have access to the data. We will ensure that any information we include in our report does not identify you as the respondent. However, in case you told me anything that led me to believe that someone else or you might be at risk from harm, I may not be able to keep what you tell me confidential.

This study has been approved by the Ethics Chair of the Research Department of Clinical

Educational & Health Psychology [Project ID No: CEHP/2016/551].

If you consent to the above, please sign below:

Interviewee

Researcher

Date

Appendix M: Research summary for participants and participating services

Learn With Us research summary: An evaluation of a film-based workshop programme for support workers of people with learning disabilities



Working in Partnership with Family Carers

Acknowledgements

This report refers to the *Learn With Us (LWU)* training project. It was initiated by Islington family carers, who developed it in partnership with Islington Social Services Learning and Development Team and Centre 404.

The evaluation presented in this report was conducted independently by researchers at University College London (UCL).

The views presented in this report are those of support workers and other staff members who participated in the LWU training sessions and of the research team. The report does not represent the official views of Islington Social Services Learning and Development Team or the services participating or UCL.

Research Team

Nadia Dandan, Doctorate in Clinical Psychology, UCL (Principal Investigator)

Dr Katrina Scior, Division of Psychology and Language Sciences, UCL

Dr Henrik Lynggaard, Clinical Psychologist

Clare Palmer, Family Carer, Trainer and Producer of *Learn With Us*

For queries relating to this document please contact:

Nadia.dandan.16@ucl.ac.uk

k.scior@ucl.ac.uk

1. Introduction

Families often have life long experience and involvement in providing care and support to their adult sons and daughters with learning disabilities. Research has become increasingly interested in how partnership working between families and care services can be enhanced.

One way of involving family carers is through co-facilitating training. In fact, research has shown that, when family carers participate in educating and training the people who work with them, this can result in positive results for them, for learners and for employers.



Learn With Us (LWU) is a film-based training package produced by family carers in partnership with support staff and their managers, and funded by Islington Social Services Learning and Development Team. Its primary aim is to allow families and staff members, particularly support workers, to understand each other better and improve partnership working to eventually benefit people with learning disabilities.

The half-day training presents filmed interviews with family carers, managers and support workers and invites participants to reflect on how to manage issues such as partnership working, choice and best interests through group activities and discussions.

2. What did we look at?

The aim of this study was to examine whether the training was successful in increasing **empathy, perception of disagreement, partnership and collaborative decision making** of support workers towards family carers.

The three participating services were: Centre 404, the In House Team London Borough of Islington Social Services, and the Complex Community Opportunity Services London Borough of Westminster Social Services.

A total of 68 support workers and other staff members completed questionnaires before and after the training. The three questionnaires were:

- ❖ The Interpersonal Conflict Scale
- ❖ The Staff Empathy towards individuals whose Behaviour Challenges Questionnaire
- ❖ Situational judgment tests (six scenarios created to represent on the job experiences)

Seventeen participants completed the questionnaires again after three months. Additionally, nine participants met with the researcher for an in depth interview. The interview's aim was to gather in depth information about the training process in general and specifically, its impact on a personal and service level.



3. What did we find?

a. Empathy

Support workers and staff's scores on the measure showed an increase in empathy towards family carers immediately after the training. However, we were not able to conclude from the measures that this had been maintained at three months follow-up. This suggests that although participants felt more empathic towards family carers immediately after the training, they did not experience that same increase in empathy in the long-term.

Nonetheless, the participants who spoke to the researcher talked about how the training helped them see things from family carers' point of view and as such increased their empathy towards them. Mainly, they spoke about an increased ability to recognise the struggles/anxieties of family carers and how to adopt more flexible styles of interactions.

'I have seen in myself the change [after the training], because I tend to be quite judgmental and I say 'well why don't they look after them better, why don't they do (...). So putting myself in their place and saying 'okay but they do it with love, with the most they can do', I have learnt to not be that judgmental or being at least more aware.' (P6)

b. Perception of disagreement

Support workers and staff's perceptions of disagreement on issues relating to everyday care, between themselves and family carers increased from baseline to three months follow-up. This could indicate that the training had raised participants' sensitivity and awareness of the areas where disagreement can occur.

During the interviews, participants spoke about conflict management and strategies to increase positive work relations with family carers. They described genuine interactions as ones that are based on trust, honesty and transparency.

'I mean again this is kind of how you work with service-users' families but even with my colleagues I might not always agree on how best to approach things, so definitely it has kind of made your perspective change to see how to deal with those situations.' (P8)

c. Partnership and collaborative decision making

Responses to partnership work and collaborative decision-making did not significantly increase immediately after the training or at three months follow-up.

Nonetheless, during the interviews, most participants spoke about ways they could increase partnership work with family carers and some discussed actual plans for increasing collaboration. For instance, they thought about involving family carers through making more contact with them and asking for their opinions. They also reflected on their role within the culture of their work environment. They were aware of some of the practical limitations that their services could pose, yet were motivated to actively work towards more integrated person centred support.

'I think it was great because you kind of see things from all perspectives and really you see what the aim is, it's for us to work in partnership with each other and that was like illustrated through the training course very well I think. (...) Even physically having them [family carers] there at the training, showcases the fact that that's our goal to work in partnership with each other.' (P9)



d. The overall experience of the training

Participants interviewed commented on two main positive aspects of the training. First, they spoke about the content of the material presented, stating that the videos and case discussions were realistic as well as informative. They felt that the training was an opportunity to openly address certain issues they faced in their work and interactions with family carers. Secondly, **participants particularly appreciated having family carers as co-facilitators, saying their active contributions made the experience much more realistic and valuable.** It also modeled the aim of the training i.e., working in partnership with each other.

Five interviewees suggested that it could be improved in two areas. First, they felt more involvement from people with learning disabilities would be helpful. Secondly, some interviewees thought that the training sessions needed to be treated more as a reflective space rather than a one-off session.

'I really liked it, I thought it was different, like it's completely different than the other training I've done before, (...) a topic I've never had training in before, it was a lot of more gentle and emotional rather than sort of like numbers and facts and things like that. So, it was kind of a warm experience rather than just sort of bullet points.' (P3)

4. Conclusions and recommendations

Conclusion 1: The LWU training was perceived as a valuable and meaningful training by participants. Its unique and effective format enabled participants to develop an increased understanding of and empathy with family carers' perspectives.

Recommendation 1: Support workers valued having family carers as co-facilitators and their participation appeared an important component to a successful training experience. Accordingly, the model of having family carers and service managers co-deliver the LWU training appears an important aspect at its success and should continue in the future delivery of the LWU training.

Conclusion 2: Support workers missed the input of people with learning disabilities' and wanted to hear the opinion of some of the individuals they were supporting.

Recommendation 2: The developers of the training could potentially work on modifying some of the group exercises to explicitly bring out the perspectives of people with learning disabilities. The third LWU film is currently in production. It focuses on skills and strategies useful in difficult situations, and portrays dilemmas and disagreements that include everyone on the LWU triangle

Conclusion 3: The content of the training was well received but participants thought that a one-off session could run the risk of having a short-term impact.

Recommendation 3: It is important to consider how the discussions initiated in the training can be continued, for example, by including reflective spaces to discuss the changes staff are making in response to the training in staff meetings and individual/group supervision.