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## **Overview**

This portfolio has three parts:

**Part one** – A systematic literature about the effects of choice for people with learning disabilities.

**Part two** – A qualitative research study using Interpretative Phenomenological Analysis (IPA) about the experience of carers in facilitating choice for people with severe and profound learning disabilities.

**Part three** – Appendices with documents relevant to the research project. Also includes a reflective statement about the experiences of putting together this portfolio.

*This paper is written in the format ready for submission to 'Journal of Applied Research in Intellectual Disabilities' (See appendix 1 for author guidelines)*

**The effect of choice for people with learning disabilities: A systematic review**

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## **Abstract**

### *Background*

Choice constitutes a core element of the human experience. To deny this right can be seen as a denial of basic human rights and yet for people with learning disabilities this has often been a reality. Some argue that choice is different for people with learning disabilities for a variety of intellectually based reasons. The effect of choice on people with learning disabilities therefore is an important area of concern for researchers to establish the underlying meaning and drivers for increasing choice for this group of people.

### *Method*

A systematic literature review was conducted to bring together studies examining the effects of choice for people with learning disabilities. The review utilised three databases and selected reference lists to find relevant articles and these were brought together in a summary of findings.

### *Results*

Studies focused heavily on task behaviours and challenging behaviours and whether and how this would be altered by introducing elements of choice or preference. A large majority of studies demonstrated that the main basis for the improvement of tasks and behaviours was the introduction of preferred stimuli rather than the being able to actively choose between stimuli. Other studies demonstrated that choice has a positive effect on mood, quality of life and motivation during a self care exercise.

*Conclusion*

Choice is complicated by the influence of preference and it can be difficult to separate out the effects of actively choosing on observed effects. Importantly choice, for whatever reason, has a positive influence on various aspects of a person with learning disabilities' life and can have negative consequences if taken away. It is important therefore that choices are examined on a regular basis to ensure that these are being met for individuals with learning disabilities in the same way as it would be for people without learning disabilities.

*Keywords*

Choice, preference, learning disabilities

## **Introduction**

The concept of choice as an area of academic research has developed out of philosophical and psychological roots as an interesting and important factor in human life. We would perhaps expect individuals to have a desire to have control over their lives and that control involves the ability and opportunity to make decisions about events that affect our lives. Choice can be viewed as a key component of empowerment where individuals maintain control over their own lives and as such increase their ability to influence their future goals and ideals (Jenkinson, 1993).

When it comes to having choice and being independent people with learning disabilities historically have been left behind (Shevin & Klein, 2004). The history of services for people with learning disabilities shows that choices may be directly or indirectly limited due to various factors which have limited the availability of choice for people with learning disabilities. Grove et al (1999) have described a number of factors which can cause difficulties in choice making for people with learning disabilities including difficulties being understood, tendency to agree to suggestions by others and ambiguity about the meaning of methods of communication. Studies have shown that in comparison to people without a diagnosis of learning disability, people with learning disabilities have fewer choices made available to them including food, clothing and who they want to live with (Kishi et al., 1988). However this does not necessarily have to be the case and studies have shown that using video training methods for people



with learning disabilities can increase levels of understanding and enable them to weigh up information to make decisions (Dunn et al, 2006).

Despite choice being an important humanistic concern it may be more complicated to provide full choice for people with learning disabilities because these are often vulnerable individuals who may be physically less capable of taking part in all activities and allowing free choice may put them at risk. For individuals who perhaps are less able to consider all the consequences of a decision regarding for example choices around food, issues around health can become prevalent and important to consider for those supporting them (Smyth & Bell, 2006). However Perske (1972) has said that taking away choices on the grounds of risk prevention actually is an act against a person's dignity. It is therefore a difficult line to tread for carers and families who support people to make decisions to avoid limiting their right to lead a dignified life. Furthermore, choice relates to an important part of forming an adult identity allowing more freedom and independence, which Jenkinson (1993) argues should not be any different for people with learning disabilities. Jenkinson also points to the distinction between different models of choice where choice is defined in normative or descriptive ways. Normative means to make a decision based on ideals and therefore without practical limitations, and descriptive describes choice based on a balance between goals and practical limits to these. Choice therefore is mediated by environmental factors, which may be further complicated for people with learning disabilities who may lack experience in making decisions.

The definition of choice itself is contentious (Harris & Road, 2003), however for the purposes of this review the Oxford definition best encompasses the meaning of choice as *“an act of choosing between two or more possibilities”* (Oxford University, 2010). Ryan and Deci (2006) have written extensively about concepts surrounding choices such as autonomy and self determination. According to Ryan and Deci being autonomous, that is to have control over one’s life, is an essential part of being human. Self determination involves active involvement in one’s life and giving this personal direction, Ryan and Deci (2000) see this process as a crucial element of healthy human development.

Importantly the literature on choice makes a clear differentiation between the act of making choices and being offered a choice previously judged to be preferred in some way (Ryan and Deci, 2006). The difference between these two concepts is that one (choice) involves personal volition in the act of getting to the other (preference). Researchers have acknowledged this difference by examining the effects of preferred activities over non preferred activities. Green et al (1997) studied preferences and happiness scores for people with learning disabilities. This study showed that offering individuals items that had been assessed previously and deemed to be highly preferred led to significant increases in happiness scores. A second important finding of this study was the clear difference between carer assigned preference and assessments based on observation of approach behaviour of the individuals: carer assigned led to lower happiness scores thus highlighting the potential conflict between proxy decision making and individual decision making.

Having choices does however come with a few provisos about the limits to its usefulness. In particular some authors have argued that to have lots of choices does not necessarily lead to positive outcomes. In the general population it may for example lead to feelings of anxiety about the act of decision making (Schwartz, 2000) or as Baumeister et al (1998) argue involve using high levels of energy for little benefit. Other research shows that having too many options can reduce motivation to take part in other activities (Iyengar & Lepper, 2000) and this picture is further complicated by differential impact of choice depending on its perceived attractiveness (Botti & Lyengar, 2004).

For people with learning disabilities choice has also proven to be a double edged sword and in many cases has been seen to have limited if not negative effects on individuals. In an interesting ethnographic account of his work with a person with a learning disability, Schelly (2008) shares stories about how his attempts to offer choices elicited less positive responses than when the individual was enabled to be more dependent upon him.

It is clear therefore that choice involves a balance between feeling in control and being actively involved in one's life but also not feeling overwhelmed by too many decisions. Given the complicated nature of choice making as a part of being autonomous and self determined researchers have been interested in exploring these experiences of choice making of people with learning disabilities in order to understand how choice implicates upon their lives and in what way. This review seeks to bring together the

research literature about the specific effect choice has on various aspects of the lives of people with learning disabilities.

## **Method**

### *Search procedure*

The databases CINHAL, PsychINFO and Medline were employed to search for relevant articles. Articles retrieved as well as relevant review articles were hand searched to include articles not found during the database searches. The search terms used were:

*“Choice”; “autonomy”; “self determination”; “decision making”; “options”; “preferences” and “Learning disabilities”; “learning difficulties”; “mental retardation”; “intellectual disabilities”; “intellectual difficulties”*

Articles retrieved were reviewed according to the following selection criteria:

- English language articles.
- Articles from peer reviewed journals only for quality control purposes.
- Includes research involving individuals diagnosed with at least mild learning disabilities; delayed development or emotional disorders to be excluded.
- Includes research involving the active process of choice making i.e. offering individuals the opportunity to make a choice and observing the consequences; indirect choice making to be excluded.
- Studies involving mixed design, qualitative or quantitative methods to be included.

The review process proceeded in three stages as follows.

1. Articles were initially reviewed by title and relevant articles were included in a secondary search.
2. The secondary search involved reviewing the articles according to abstract information and from this further articles were either included or excluded.
3. Finally articles were reviewed in full text form to examine whether they were suitable for this review. Articles chosen to be included were reviewed according to a quality checklist.

#### *Data extraction*

Relevant information was extracted from the studies using a data extraction form (Appendix 2) which involved recording the title, journal details, methods used and the variables that were measured and the results found.

#### *Data synthesis*

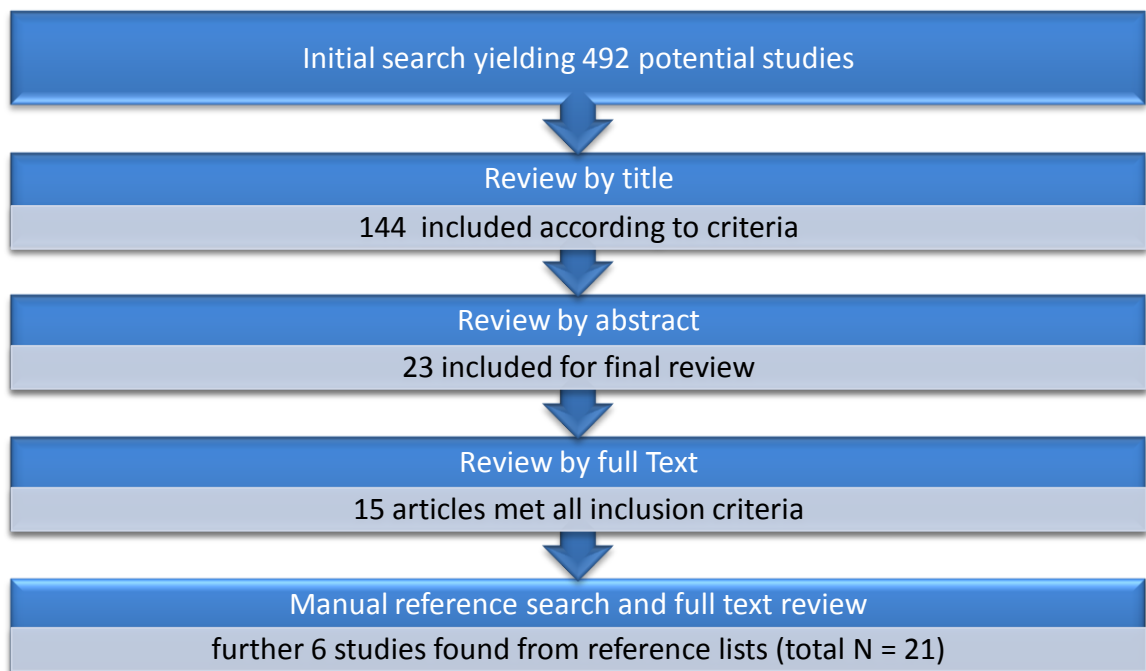
The data extraction table was used to provide a summary of all the included studies. A descriptive format was then utilised to group studies according to similar effects studies and the specific outcomes observed. An overall summary across all studies was then created.

### *Assessment of Quality*

An adapted quality checklist by Harden et al (2004) was used to assess the quality of studies included. This included a set of 7 quality indicators assessing aspects relating to background information, aims, context, sampling, methodology, reliability and validity and relevant inclusion of raw data. Each criterion was marked on a likert scale of 1 to 4, with 1 (poor) being the lowest and 4 (excellent) being the highest. To aid these figures a supplementary descriptive analysis of study quality was also included. See appendices 3 and 4 for the quality checklist table detailing criteria and table of full scores.

## **Results**

The outcome of the selection procedure can be seen in Figure 1. The search conducted yielded 492 articles to be reviewed. From these 144 were then included in the secondary search based on review by title. These were then further examined by abstract information, which led to the inclusion of 23 articles. These final articles were reviewed in full text form and a further 8 were excluded for failing to meet the inclusion criteria. The reference list of included articles was reviewed manually and from this 6 further studies were included in the final write-up.



*Figure 1. Article selection process*

## **Methodology**

### *Participants*

The age range of the participants of all the included studies was 4 – 76 years of age.

The studies covered a range of learning disabilities including mild, moderate, severe



and profound. Specific numbers for each learning disability classification was not available from all studies. The participants included students, residents in care homes, independent individuals living in community settings and people who were employed. One study included the views of direct care staff as well as people with learning disabilities. The recruitment procedures used were similar across studies and involved contacting managers of care homes or teachers in academic institutions who were asked to make suggestions about who would be suitable for the study.

### *Materials and procedures*

A range of materials and procedures were employed in the studies. To assess the impact of choice researchers utilised a variety of tasks, stimuli and activities, including choice of activity, clothes, food, academic or work task. Various informal preference assessments were used to categorise stimuli and tasks into preferred and non-preferred categories. In carrying out the experiments studies also used a number of relevant task materials including ironing equipment, work materials (wood, tools etc), educational assignments and Micro-switches.

Measures used to assess choice included the Resident Choice Scale (Hatton et al, 2004), the Broad Independence Score (Bruininks et al, 1986) and the decision making scale of the Multiphasic Environmental Assessment Procedure (Moos & Lemke, 1984). The Vineland Adaptive Behaviour Scale (Harrison, 1985) was also used to assess the effect of choice on behaviour and researchers also employed idiosyncratic measurements of behaviours by monitoring the number of times a certain activity occurred such as number of times the paint brush was dipped into the paint.

### *Design*

Eighteen of the 20 studies were quantitative in nature, employing specific experimental variables and comparing these across conditions. Studies employed multiple cross comparisons of different conditions including preference as well as choice or single comparison across two conditions of choice versus no choice. One of the studies employed a mixed design including both qualitative interviews and quantitative measures which were compared using a hierarchical regression of the included variables. One study employed a qualitative design using semi structured interviews of people with mild learning disabilities about their personal experiences of choice.

### *Analysis*

As shown in Table 1. the quantitative studies employed a variety of methods of design and analysis. All studies conducted a cross comparison experiment with varying numbers of conditions including baseline measures. Four out of 18 quantitative studies conducted statistical analysis on the data with the majority reporting average results for each condition.

Study	Participants	Variables	Design & Analysis	Statistical procedure	Outcome
1. Killu et al (1999)	N = 3 Unknown learning disability 12 – 13 years	Preference and choice on academic task engagement	Simple design 6 experimental conditions: Choice - preferred; choice - non-preferred; no choice - preferred; no choice - non preferred; no choice - preferred (control); no choice - non-preferred (control)	None	Choice had no substantial benefits over no choice, lowest task engagement was in 'no choice, no preference' condition.
2. Parsons et al (1990)	N = 4 'severe handicaps' 31 – 38 years	Preference and choice on work 'on-task' behaviour	ABAB (alternating) design Comparison across multiple conditions (assigned high preference, assigned low preference, choice)	None	Preference and choice increased 'on task behaviour'. Assigning preferred task is as effective as being able to choose.
3. Lerman et al (1997)	N = 6 Severe to profound learning disability 4 – 39 years	Preference and choice on reinforcing stimuli	ABAB design Comparison across baseline and two conditions (choice and no choice) plus yoked control (no choice)	None	No difference between choice and no choice conditions
4. McKnight	N = 8	Choice on measures –	Single baseline, multiple measures (scales	None	No significant difference between adaptive

& Kearney (2001)	Mild (1), Moderate (5), Severe (2) learning disability 20 – 42 years	Resident Choice Scale and Vineland Adaptive Behaviour Scale	and questionnaires)		behaviour after introduction of choice training
5. Kennedy & Haring (1993)	N = 4 Profound learning disability 5 – 20 years	Preference and choice on stimulus engagement using Micro-switch	ABAB design Comparison across baseline and two experimental conditions (self choice or other choice) plus control condition (preferred without micro-switch)	None	Increased engagement when given choices via micro-switch, preferences changed over time.
6. Stenhoff et al (2008)	N = 1 Unknown learning disability 15 years	Choice on percentage of assignment completed and percentage correct	ABAB design Comparison choice and no choice	None	Choice increased academic task completion and percent correct.
7. Lancioni et al (2007)	N = 9 Severe or profound learning disability	Choice via Micro-switch on indices of happiness	Simple design Comparison choice and no choice	None	2 of 9 did not show differences between baseline and post intervention indices of happiness. 4 of 9 had statistically significant

	3 – 18 years				increases in happiness indices.
8. Bambara et al (1994)	N=5 Severe learning disability Unknown age range	Preference versus choice and no choice on academic task behaviour	ABAB design Comparison across multiple conditions (assigned high preference, assigned low preference, choice)	None	Highest 'on task behaviour' was in both 'preferred assigned' and 'choice' conditions, worst condition was 'no choice low preference'.
9. Seybert et al (1996)	N= 3 Unknown learning disability 14-21 years	Choice on problem behaviour; happiness indices and task engagement	ABAB design Comparison across multiple baselines and multiple conditions (choice and no choice)	None	Choice was related to reductions in occurrence of 'problem behaviour', 2 students appeared more interested in their tasks when given choices, happiness did not increase.
10. Verpillot & Datillo (1995)	N=unknown Mild learning disability 21-65 years	Interviews of people with mild learning disabilities	Qualitative design	None	Negative feelings reported about choice restrictions, anger most commonly cited.
11. LaMore & Nelson (1992)	N= 22 Mild – severe learning disability 24-76 years	Choice versus no choice on number of times subject dipped paintbrush into paint and applied it	Simple design Comparison across 2 conditions, choice and no choice	Matched pairs signed rank test	Subjects painted more and for longer when they had options at the beginning than when they did not.

12. Rice & Nelson (1988)	N= 24 Unknown learning disability 15-26 years	Choice versus no choice of t-shirt on effort during ironing task	Simple design Counterbalanced single comparison across choice and no choice conditions	None	When given the choice of t shirt they gave more care than when there was no choice.
13. Heller et al (1999)	N=58 25% Mild learning disability, 14% moderate learning disability, 59% severe to profound learning disability 32-74 years	Various questionnaires around choice and quality of life measures	Simple design Baseline and 5 conditions (only one was choice, other conditions not discussed)	None	Greater opportunities for choice were associated with greater 'adaptive behaviour', higher levels of community integration and further interest in activities.
14. Neeley-Barnes et al (2008)	N=224 50% Mild learning disability, 30% moderate learning disability, 7% severe learning disability	Assessment of quality of life according to living arrangements, levels of choice, community inclusion, rights, relationships and	Mixed design Single baseline, multiple measures (scales and questionnaires)	Chi-square Test; Comparative Fit Index; Weighted Root Mean Square Residual	Greater choice and smaller living arrangements were associated with increased quality of life. Greater choice was associated with experiencing more protection of rights and greater access to the community.

		proxy decision making			
15. Datillo & Rusch (1985)	N=4 Severe learning disability 8-12 years	Choice of leisure activity on engagement in activity	ABAB design Comparison across multiple baselines and multiple conditions (choice and no choice)	None	Children were able to make active decisions about leisure activities and were more therefore more engaged in these activities.
16. Schartzman et al (2004)	N= 4 Severe to profound learning disability 31-45 years	Preference and choice on measured happiness	Simple design Choice across three conditions (high, medium and low preference)	None	1 participant showed no happiness indicators throughout. Generally happiness indicators were low and were not related to choice making
17. Smith et al (1995)	N=4 Profound learning disability 33-34 years	Choice versus no choice on measured approach behaviour to stimuli	ABAB design Comparison across multiple baselines and multiple conditions (choice and no choice)	None	Preferred stimuli significantly increased number of behavioural responses. No significant difference between choice and no choice
18. Vaughn & Horner (1997)	N= 4 Moderate to severe learning disability 7-12 years	Preference and choice on target behaviours identified	ABAB design Comparison across multiple conditions (assigned high preference, assigned low preference, choice)	None	Rates of 'problem behaviour' were lower with high preference items regardless of teacher or student assignment, one participant showed a slight preference for the choice condition.

19. Dyer et al (1990)	N= 3 Developmental delay and severe 'retardation' 8-11 years	Choice on behaviour during educational task	ABAB design Comparison across multiple conditions (assigned high preference, assigned low preference, choice)	None	Choice making significantly reduced measured 'problem behaviours'.
20. Cole & Levinson (2002)	N= 2 Severe learning disability 7-8 years	Choice versus no choice on challenging behaviour and steps of tasks completed	ABAB design Comparison choice and no choice	None	'Challenging behaviours' were reduced in the choice condition and deteriorated in the no choice condition. More steps of the task were completed with choices.
21. Dibley & Lim (1999)	N= 1 Severe learning disability 15 years	Preference and choice on task initiation and protesting behaviour	ABAB design Comparison across multiple conditions (assigned high preference, assigned low preference, choice)	None	Choice increased task initiation and decreased protest behaviours

Table 1. Methodology and results of all included studies



The single qualitative study (10) employed a method of constant comparison method of analysis (Glaser & Straus, 1967) and employed methods of 'coding' of data to establish concepts emerging from the data and 'memoing' which utilised researcher notes and reflections.

### *Quality assessment*

Across all studies the highest possible score for any individual criterion was 84 (4 x 21 studies). The main strength of all the studies was having a clear description of the method and procedures used in the study. This produced a score of 77. The lowest figure was for the criteria based on clear aims and objectives, which scored 60. Across all criteria for any individual study the highest possible score was 28 (4 x 7). Overall across all criteria the highest scoring study was number 14 which scored the highest possible score of 28. Lowest scoring was study 8 because it was a replication study and as such did not include as much information.

The majority of the studies utilised small samples, which is inevitable given the nature of the client group and the time needed to conduct experiments when using creative techniques (e.g. micro-switch training). The small sample sizes would probably limit the generalisability of the findings as the power level would be small and statistical analysis would not be possible. Despite these limitations most of the studies (N =18) included measures of inter-rater reliability due to the observational nature of the variables identified.

In scoring the studies the main factors for consideration were based upon whether there was theoretical justification for the study, how easy it would be to replicate the study based on the information provided and whether the conclusions are supported by the information provided. All studies scored well on all of these criteria and in particular as already noted researchers paid a great deal of attention to describing materials used and how the studies were conducted. Study 14 which scored the highest possible score of 28 was a lengthy article and had paid a great deal of attention to describing all aspects of the process and in reading this it was very clear how the study had been devised and how it progressed. This study's findings can therefore be considered to be more valid as a result of this attention to detail.

Another notable consideration for the quality of the studies which is not covered specifically in the quality checklist is the attention to issues of consent. Whilst recruitment procedures and information regarding the methodology were a strength of the studies included, there was a lack of information regarding whether and how consent was considered for the people being studied. Whilst this does not strictly affect the ability of the authors to make conclusions regarding the study it does constitute an ethical concern for a group of individuals who may be considered vulnerable. Offering fully informed consent may have been a difficult process for people with alternative forms of communication and may have biased the results of the study if participants were aware of the purpose, however it is debatable whether this justifies not reporting on these important considerations.

## *Findings*

Table 1. presents the methodology and overall findings of the studies. The studies assessed how choice implicated upon different areas and examined whether choice would increase or decrease these variables.

The focus of the studies clustered around 6 key areas; Being on task, Engagement in activities, Behaviour, Mood, Quality of life and Self care.

### Being on task

Studies included looked at the effects of choice on being on task for people with learning disabilities. These studies looked at the way choice might improve the focus of individuals at the task at hand and how quickly and effectively these tasks were conducted. Studies 1, 2, 3, and 20 demonstrated that choice improved the focus on and engagement in both academic and work based tasks. This was measured by observing how much individuals used task materials, whether they followed task instructions and how much they were distracted to non-task stimuli. The studies also demonstrated choice had no greater effect than being presented with a highly preferred task. The authors of these studies conclude that this demonstrates that the act of choosing itself is not more effectual than simply being presented with something already deemed preferable. The difficulty with this conclusion is that the studies did involve pre assessment measurements of preferred items which in itself may be considered part of the choosing process even though this was conducted prior to the main experiment. Study 20 similarly looked at choice versus no choice on task

accomplishment but without measuring preferences and found that choice increased the number of tasks completed.

Study 6 also looked at being on task in an academic assignment for people with learning disabilities and more specifically the amount of tasks fully completed and the number of correct responses in these tasks. This study found that choice significantly improved the number of tasks completed as well as the percentage correct from as much as 2% at baseline to 89% during the choice condition.

Study 11 assessed the number of times a ceramic object was painted when subjects were allowed to choose which object to paint at the beginning than when they had not. Participants dipped a paintbrush and made more brush strokes when they were allowed to choose than when they were not. The authors conclude that giving options in a task improves the desire of the participants to spend time painting.

### Engagement

A few studies were found which assessed the active engagement of participants in a variety of activities. Study 5 looked at the engagement of subjects in a social interaction exercise of students with profound and multiple learning disabilities. This study found that using micro-switch technology to allow students to make choices increased their engagement in the activity. The authors also noted that the preferences

obtained changed over time and used this as evidence for a need to make ongoing assessments of individuals' preferences.

### Behaviours

A number of studies have looked at how choice can affect the behaviours of people with learning disabilities. In particular research has defined problem behaviours as including “aggression”, “shouting”, “misusing objects”, “bolting”, “disruption” and “resistance” and has sought to make use of choice making in tasks to alleviate these behaviours. Study 9 showed that giving students choice of task led to reduced number of defined problem behaviours and the authors noted that students appeared more interested in their task when offered these choices. Study 12 looked at a number of variables in adults living in residential homes for people with learning disabilities and they found that having more choice opportunities led to a greater amount of “adaptive behaviours”. Study 18 compared choice across different degrees of preferred tasks and found that “problem behaviours” were reduced when offered preferred activities and that this occurred regardless of whether the student chose or whether the teacher chose among these preferences. This finding is line with other studies showing that the preferred stimuli itself creates the effect rather than the act of choosing.

Studies 19, 20 and 21 found that simply offering students the choice of task reduced the number of “challenging behaviours”. Behaviours included screaming, shouting and inappropriately using materials and the choice condition allowed individuals to have control over the nature of the task itself. Study 21 defined these behaviours as

'protests' however the description of the behaviours such as spitting and swearing were similar to the other studies of behaviours. These studies did not separate out the effects of preference on these behaviours so the process of choosing included being offered preferable stimuli as well as being allowed to make a choice.

### Effect on mood

A small number of studies were found which indicated that there may be a relationship between choice and mood for people with learning disabilities. Study 6 showed that when given choices via a micro-switch system people with severe or profound learning disabilities improved on measures of happiness, however it was noted that 2 of 9 participants in the study did not significantly increase on these measures. The difficulty with this study in particular seems to have been the identification of happiness indices and the authors do highlight that not displaying particular 'happiness indices' does not necessarily mean that these individuals were not pleased with the activities they were involved with.

Study 10 was the only qualitative study found in this literature review and was an exploration of the experiences of people with mild learning disabilities. Participants commented on the barriers to choice making and most commonly this was observed to be the actions of other people who had for a variety of reasons taken away the choices of these individuals. The authors looked at a number of factors and notably they found that the most common response to being deprived of choice were feelings of anger. Participants in this study were asked to personally reflect on what it is like to be

deprived of choices and were able to give examples of these occasions and their feelings towards being told what to do. Some participants appeared indifferent or pleased with allowing others to make decisions for them; however the majority reported feeling angry or frustrated.

### Quality of life

Study 14 was the only study found to address explicitly the relationship between choice and factors believed to be associated with quality of life. They examined different living arrangements and noted that smaller resident numbers combined with greater choice opportunities related to measures of quality of life. In particular they noted that choice was significantly influential on protection of individuals' rights and more involvement in community life. Residents who were assessed as more actively involved in the running of services had higher levels of inclusion in community activities such as community entertainment and were more likely to have their rights respected. These were taken to be indicators of quality of life by using factor analysis of different variables including relationships, community involvement and respect of rights. Choice implicated on all quality of life indicators.

### Self care

Study 12 looked at the way individuals with learning disabilities looked after a t-shirt they had received from the researchers. The authors looked at levels of ironing of these t-shirts comparing choice and no choice conditions. In the condition where participants were assigned a t-shirt participants ironed less than when they had been given the

opportunity to choose the t-shirt themselves. The authors concluded that allowing individuals to choose between options may give them more reason to take care of these items.



## **Discussion**

This literature review examined the current available literature on the effects of choice for people with learning disabilities. Generally choice appears to have an impact upon the engagement in activities, task performance and seems to encourage individuals to have more interest in these tasks and stimuli. Furthermore, choice seems to have beneficial effects on aspects of quality of life including increased levels of integration within wider communities. Perhaps choice affects these areas because individuals have more personal investment in these activities; however, the exact reason for these effects however is still speculative. The authors of a number of the studies in this area did show that allowing people to do things they enjoy was as significant as letting them choose the activity, which is unsurprising given that people are more likely to engage in something they find pleasurable over something they do not.

Furthermore, choice appears to have an impact on measures of quality of life according to one of the studies of this review. This finding is in line with related research looking at the effects of similar concepts such as self determination and autonomy on quality of life (Nota et al 2007). It is curious therefore that aspects of self determination such as personal control over environment were undermined by the finding that the act of choosing alone did not seem to be the most influential factor in improving any of the effects studied. The majority of the studies examined showed that merely obtaining a person's most preferred item or activity had the most significant effect rather than the act of being allowed to choose. This meant that there was no extra effect of being offered a preferable item when this was assigned by someone else. There is however a complication with this conclusion which is that the studies which measured choice

compared against preference did in fact obtain people's choices prior to the main study which although not temporally close to the stimulus presentation it does not rule out the possibility that participants still had a sense that they had been actively involved in choosing the item. Regardless of such difficulties in making conclusions the research has however highlighted the importance of recognising a clear difference between actively choosing and being allowed to take part in something considered enjoyable.

The type of effects covered within the studies was another interesting component of this literature review with a particular bias towards observing 'on-task' behaviour of people with learning disabilities to the detriment of other possible avenues of exploration. One such deficit is the limited amount of literature on the effects of choice on various mood states for people with learning disabilities and the two studies identified had different and therefore inconclusive findings with regard to measures of choice and happiness. The reasons behind this seeming bias could be related to the research question which assessed specific effects of choice on people with learning disabilities, which could have meant that fewer exploratory studies were included. Regardless of the reasons for such an imbalance the review does suggest that many researchers in this area have a particular focus on maintaining certain 'appropriate' behaviours rather than seeking to explore experiences and meanings of choice for individuals.

Choice not only appears to influence a person's focus on a task but also increases their motivation to work hard. The studies presented in this review found that people

performed better on academic tasks as well as self care activities, which seemed to be a function of their level of motivation based on ability to have control over these tasks. This finding seems unsurprising and again fits with other literature for people without learning disabilities which show that personal control influences intrinsic motivation and thus provides people with an incentive to do a task well (Ryan & Deci, 1985).

Despite being experimental in nature and therefore having limited data on individual differences there were some interesting points about the differential impact of choice for individuals. Three of the studies reported different choice effects for individuals with some seemingly valuing choice more than others, for example study choice increased for some participants but not for others. The reason for such a difference may be related to personal preference in relation to choice making with some individuals valuing the opportunity to actively make choices whilst others did not. Alternatively these individual differences may relate to inadequate measures of personal enjoyment; happiness is a subjective feeling and it may not be easy to differentiate happiness for people with more severe learning disabilities by observing their behaviour.

Overall this review has found that the literature on choice for people with learning disabilities follows a similar pattern to the findings in the general population where choice is valued by individuals and affects many psychological variables such as motivation (Ryan & Deci, 1985). Choice is not a straightforward concept and in this sense can be quite difficult to study experimentally. Findings suggest that the

effectiveness for choice to positively affect lives is based upon a balance of too much versus too little choice and in this sense choice can be seen to have both positive and negative effects on individuals. Choice is further compounded by the influence of preference in this process and choice can also be viewed as a relatively neutral force when the impact of personal preference is controlled for. It is, however, clearly difficult to completely separate the effects of pleasurable activities over personally chosen activities as the two are inextricably linked and this makes conclusions regarding the specific effect of choice hard to pin down. When it comes to having or not having choice there is no single influence of choice over individuals with learning disabilities, as with the general population it depends on a host of factors including individual differences, degree of choice and availability of preferences.

#### *Limitations of this review*

There are a number of notable limitations to this review. Firstly there was no clear differentiation of type of learning disability, a number of the studies employed a mixture of learning disability types meaning that examining the differences between for example mild and severe disabilities was not possible and would have allowed a more specific examination of how choice affects people with varying degrees of intellectual ability. Similarly, there was no differentiation between the age groups included in the studies. There was a wide range of age ranges of the participants with the youngest being 4 and the eldest being 74. Looking at the difference between age groups may have offered some insight on how choice may be different according to age. It might be expected that children perceive the importance of being able to choose differently since childhood includes lower levels of control over situation and

are expected to follow the rules set by adults. An examination of the differences between the different age groups of the included studies does, however, suggest that the effects of choice were similar regardless of participant age. The picture for studies using children shows a similar pattern to those using adult participants with a mixture of positive and neutral effects. Studies 1, 15, 18, 19, 20 and 21 all employed only children and these found that, in the main, having choice or preference was beneficial. The reason for this similarity across age groups can only be assumed and may suggest that younger people with learning disabilities have a similar need to adults to have choices available to them and to be able to take part in the activities that they most prefer.

The range of studies found was also limited and the review seems to have drawn a bias towards studies looking at educational achievement and behaviours during tasks. It is not clear whether this is due to scarcity of studies looking at other specific effects of choice such as different mood states and personal factors such as self esteem or whether this is the results of the method of review. Given this apparent bias towards achievement and behaviour there is an uncomfortable sense that researchers are mostly interested in affecting people with learning disabilities to behave themselves according to a set standard rather than being interest in the personal benefit of the individuals themselves.

The final limitation of this review is a philosophical one, namely the implications inherent in the aims of the review. There is an underlying assumption within this

review that there should be differential effects of choice for people with learning disabilities. Although there is evidence to suggest that choice making is a different process for people with learning disabilities than people without it may not be reasonable to assume that choice affects them differently. Furthermore as already noted, choice is a very personal process for all individuals and it should not be assumed that choice will have similar benefits for everyone. Choice may affect one person's motivation and have very little impact on their happiness and conversely another individual may get personal enjoyment from choice but have no beneficial effects on their levels of motivation. The qualitative study of this review offers a more personal viewpoint of choice and clearly demonstrates the value of choice for people with learning disabilities.

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**'The experience of carers in facilitating choice for people with severe and profound learning disabilities'**

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## **Abstract**

### *Background*

Over the past few decades there has been a steady change in the care of people with learning disabilities with a move towards greater levels of social integration in line with the rest of the population. The government white paper, Valuing People (Whitaker & Porter, 2002) set out a vision for individuals to receive the same treatment and respect as the rest of society. In keeping with these aims is the right to choose, a basic human right for all members of society. Difficulties seem to arise when a person lacks the ability to express their choices to others and it is with these others that the responsibility to access that choice lies.

### *Methods*

Eight carers and support workers responsible for supporting people with severe and profound learning disabilities were recruited to take part in an exploratory study into their experiences as facilitators of choice. A qualitative approach (Interpretative Phenomenological Analysis) was used to systemically analyse semi-structured interviews.

### *Result*

Carers described a variety of factors that both helped and hindered the facilitation of choice for the people they supported, choice was described as being quite complicated at times and various measures were put in place to aid this. Participants discussed systemic factors such as the number of residents, practical limits on time such as paperwork and spoke of the importance of knowledge and training. Participants also spoke of their feelings of frustration towards these limitations.



### *Conclusions*

The study generated some interesting and important insights into the experience of people supporting individuals who communicate without words. Practically the study highlights the restrictions on interactions between carers and service users through the necessity of large amounts of paperwork. Furthermore the discussion highlights the importance of the relationships between the individuals living in shared accommodation and those who support them. Limitations of the research and future recommendations are discussed.

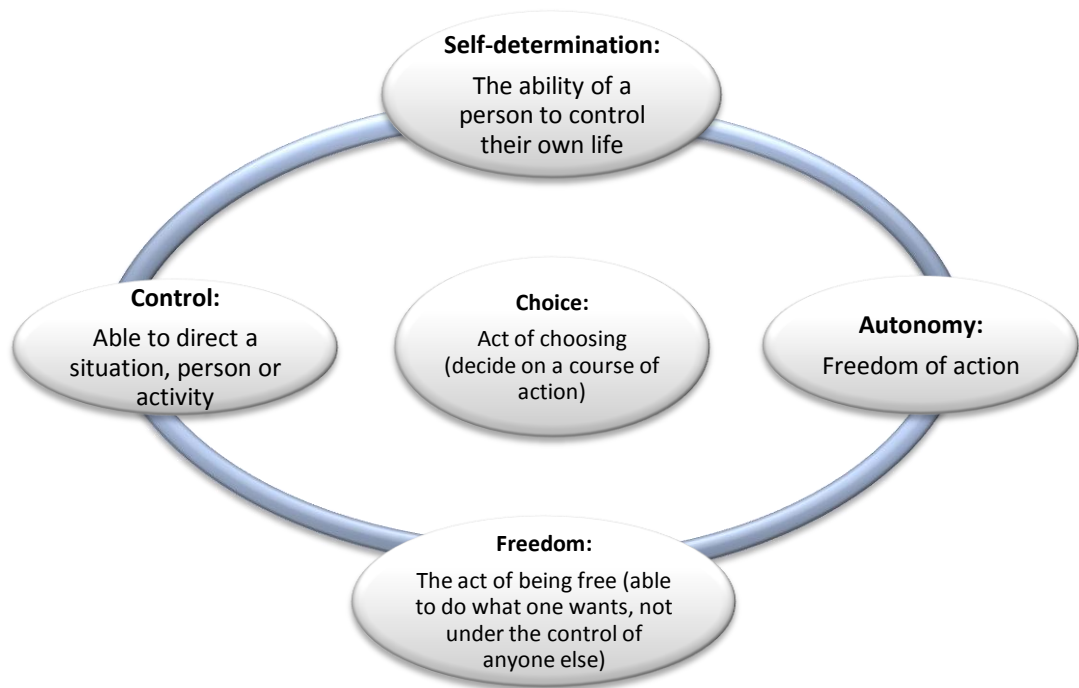
Keywords: Severe and profound learning disabilities, IPA, carers, choice

## **Introduction**

The Human Rights Act (1998) has been a key document in enshrining and promoting the progressive values of modern society. Within it the rights of individuals to control their lives at will is made clear:

*“Everyone has the right to liberty and security of person” (article 5, line 1)*

The Oxford English Dictionary (2005) describes freedom as being the power or right to act, speak or think as one wants. Being able to choose a course of action therefore can be viewed as a basic human right, enshrined in both law and the common consciousness of society. On the surface choice is a simple concept based around the idea of being able to select between a number of alternatives. Beyond definition however choice lends itself to a whole host of interesting and complicated issues. The diagram below outlines the range of concepts related to the act of choosing as identified through the Oxford English Dictionary.



*Figure 1. Choice and related concepts*

As the diagram shows choice exists within a broader network of ideas around being in control, determining one's own life and being free to do what one wants. In this respect choice can be seen as a universal need and research shows that choice, and in a broader sense self determination, has benefits for the psychological health of individuals (Owens et al, 1996).

*Choice, self determination and autonomy have beneficial effects*

In the general population in the area of health, having choices has been linked with lower levels of tension, depression, anxiety and a lower need to have more information about issues around health (Ogden al, 2009). Furthermore, Ogden and colleagues have shown that having choices has been linked with higher feelings of satisfaction and a sense of control. Interestingly Ogden et al found that the beneficial effects existed for having the option to choose but the act of fulfilling the choice did not differ

significantly from baseline. This led the researchers to suggest that the beneficial effects of choice came from simply having multiple options rather than seeing the choice come to fruition.

### *Learning disabilities*

In 1998 Wehmeyer and Schwartz conducted a study looking at the relationship between self determination and quality of life. The study included 50 adults diagnosed with intellectual disabilities and carried out measures of both self determination and quality of life. They found that there was a relationship between the two constructs with individuals exhibiting signs of high self determination also showing higher levels of quality of life. These findings were replicated in a study by LaChapelle et al (2005) who conducted an international study across Canada, the U.S, Belgium and France and again found that people who were deemed part of the high self determination group having higher reported levels of quality of life. In other research choice has been identified as a key factor in the expressed satisfaction of people with learning disabilities (Gregory et al 2001).

Choice, it would seem, has psychological benefits as well as being of vital importance in fulfilling basic human rights for people with and without learning disabilities.

### *People with learning disabilities can make choices*

Historically individuals with learning disabilities of all kinds were deemed unable to make choices. Even in today's society capacity is assessed to ensure that individuals are able to weigh up arguments, make a decision and communicate that decision to others, a process that can be limited for people with lack of verbal abilities. Several studies however have shown that there is a large number of ways in which people with

learning disabilities who cannot talk are able to express preferences. Such means have included technology such as switches (Lancioni et al., 2004) and the use of proxies who know individuals well and are able to make inferences based on common responses to stimuli (Cummins, 2002). There are however complications to ascertaining choices from people with profound and multiple learning disabilities, for example Ware (2004) argues that the large amount of inference involved makes understanding the decisions made by individuals who cannot communicate verbally rather difficult. Ware also adds that the people making the inferences are usually the people who are most emotionally invested in the individuals they are supporting and therefore it is difficult to separate out personal motives from actual and objective inferences of behaviours. Ware concludes that there needs to be an honest approach towards accessing decisions, which includes acknowledging that this will always be limited if we do not make use of more objective measures such as switches.

### *Purpose of study*

Given the complicated nature of choice and the verbal limitations prevalent with people who have severe learning disabilities the necessity of using proxies to make their decisions becomes apparent. For people living in residential or supported living groups these proxies are usually the carers who support them and it is on these individuals that this study will focus. The aim of the study is to explore the complicated process of accessing the choices made by individuals with severe and profound learning disabilities and establish what this process is like for them. The hope is that this will provide insight into the interactions between the people making a choice and the facilitators of that choice in order to learn about ways in which this process can be made easier for both individuals.

The research questions following broadly from these aims are:

- How do carers facilitate choice for people with severe and profound learning disabilities?
- What is this process like for them?
- How might the facilitation of choice be made easier for carers of people with severe and profound learning disabilities?

## **Method**

### *Recruitment*

From the 13 residential homes approached 8 individuals from 7 different residential homes volunteered themselves to take part in the study. A further 2 residential homes offered the names of 4 individuals who might be able to take part, none of these individuals agreed to take part when approached. Those who declined to take part explained that they did not have time to take part in the research (n=3) or that they would be leaving their post soon and would not be able to take part (n=1).

### *Participants*

Overall 8 carers or support workers from 7 different residential homes or supported living environments within the Humberside area took part in the study. Seven of these were female and there was one male participant. The average age of the participants was 33 years and the range was 22 – 43. The average level of experience working with people with learning disabilities was 8 years and it ranged from 8 months to 23 years. Seven out of 8 participants worked full time and one worked part time. Most (7/8) respondents said that they had some training relevant to the topic of choice in the past 12 months. The age range for the people living in the residential homes was 18 to 80 years. The average number of staff members in each setting was 14 with a range of 5 to 24.

Table 1. details information about individual participants, their demographic information, work environment and amount of experience working with people with learning disabilities.

Participant	Pseudonym	Gender	Work environment (Service users)	Experience
1	Tom	Male	Private residential (2)	3 years
2	Faye	Female	Local authority residential (2)	1 year
3	Linda	Female	Supported living (2)	3 years
4	Julie	Female	Residential private (2)	19 years
5	Tracey	Female	Local authority residential (9)	11 years
6	Pam	Female	Local authority residential (9)	23 years
7	Nicola	Female	Private residential (4)	4 years
8	Amanda	Female	Private residential (4)	8 months

Table 1. Participant demographics

### Measures

A semi structured interview was developed according to guidance by Smith and Osborn (2003) which including questions relating to the daily experiences of the participants in their work with people with severe and profound learning disabilities. The schedule was divided into four sections, the first pertaining to general questions about the role of the participants on a daily basis and their general experiences of the job. The second section related specifically to the participants' general understanding and feelings towards the idea of choice generally. The third section of the interview schedule focused on the carers' thoughts on the meanings and experiences of choice for people with severe and profound learning disabilities. The final section looked at the experience of the participants in facilitating choice for people with severe and profound learning disabilities. The full interview schedule can be found in Appendix 8.

### Procedure



Ethical consent was obtained by the University research committee (see Appendix 5 for confirmation letter). Participants were recruited by contacting residential home managers and sending further details in the form of a poster and information sheet for managers to advertise at their work place. Participants who were interested in taking part were asked to fill out a reply slip with contact details. Once participants had expressed interest they were contacted via telephone and offered further information and opportunity to ask questions. Participants were visited at their place of work in order to conduct the interviews, prior to interviewing, participants were given the information sheet again and asked to fill out a consent form (see Appendices 6 and 7). The main interview commenced which took between 30 minutes and 1 hour to complete. Participants were then asked to fill out the demographic questionnaire. The semi structured interview schedule was used as a basis for questioning participants and any points of interests were followed up as per the semi structured approach.

### *Analysis*

Once completed the interviews were transcribed fully by the main researcher allowing further immersion in the data. Analysis of the data followed the general approach of IPA as outlined in (Smith & Osborn, 2003). IPA does not prescribe a specific approach to data analysis but in general involves the initial generation of themes by reading through the transcripts several times, grouping the themes into sub headings and finally deciding upon an appropriate super-ordinate theme around which a number of themes cluster. Once the data was fully transcribed it was read over twice during which summaries of ideas and possible themes were noted in the margin. These notes were used to group the ideas into themes, which involved re-reading the transcripts and checking for consistency of themes with the ideas. Finally the themes generated were

clustered together according to common ideas. A transcript showing the process of analysis is included in Appendix 10.

To assess whether the analysis of the main researcher was a valid reflection of the meanings and experiences obtained during the interview, the research supervisor read through two complete transcriptions and completed an IPA analysis of themes. The two researchers compared the themes generated to check for consistency of results or whether any themes appeared to have been missed by the main researcher. Secondly two field supervisors who are clinical psychologists working in two learning disabilities teams read through one complete transcription and carried out an IPA analysis. Again this was checked against the findings of the main researcher for consistent and inconsistent themes generated. All of the quality checks demonstrated that the analyses generated by all the researchers were consistent and that there were no themes that had been missed by the main researcher or themes generated that did not fit with the data. The agreement between the researchers suggests that the analysis generated valid themes.

## **Results**

The analysis generated 21 themes, which clustered into 6 super ordinate themes. The main themes included 'Complications of choice'; 'Responsibility and risk'; 'Enrichment & quality of life'; 'Importance of knowledge and understanding'; 'Person centred systems' and finally 'Frustration and stress'. The results are presented in Table 2.

<b>Super ordinate themes</b>	<b>Sub-Themes</b>
<i>Complications of choice</i>	Possible limitations Choices change Too much choice can overwhelm
<i>Responsibility and risk</i>	Best interest meetings Risk, vulnerability and positive risk taking Legislation
<i>Enrichment and quality of life</i>	Providing activities/ opportunities Achievement of individuals Relationships, trust and feedback
<i>Importance of knowledge and understanding</i>	Training and skills Planning and organisation Empathy
<i>Person centred systems</i>	Knowing the individuals Predictability of environment Adaptation and flexibility Against the institutions
<i>Frustration and stress</i>	Limitations of time and resources Having to say 'no' Attitudes of others

Table 1. Themes and super-ordinate themes generated

### **Complications of choice**

The first super-ordinate theme related to how choice can be complicated to provide. Participants cited times when choice is more or less difficult and how too much choice cause difficulties.

## *Sub-themes*

### Possible limitations

Participants were asked about the ability of individuals to make choices and the replies suggested a recognition that choice depends on the learning disability itself and how some individuals were more able to make choices than others. All participants felt that although most could make their choices known in some form, they did not necessarily have an understanding of the choices they were making. Within the results there also seemed to be contradictions in the responses about whether people with severe and profound learning disabilities could make choices, participants said they felt that people could make choices whilst at other times suggesting that individuals were not able to understand and weigh up the risks and consequences of their decisions. Ultimately there seemed to be a distinct recognition amongst the participants that there are limitations on what can be known about people's thoughts about the choice being offered to them. This quote from Tracey demonstrates such a feeling:

*"... without somebody saying to me 'I really want to do that' then I don't know how I would know what was going on inside their head and what they were thinking"* (Tracey, Page 6, Line 1)

### Choices change

Participants were aware that choices can change over time and some seemed more keenly aware of this than others. One participant in particular was very positive about the need to constantly re-assess choices based on the philosophy that we all can change our minds at different times, which is the same for people with severe and profound learning disabilities. Other reasons suggested for choices changing were

around the effects of ageing and an acknowledgement that over time people do change their minds about things they like and dislike. Participants were able to think of times when they had felt surprised by the choices made by individuals which seemed to reinforce the idea that re-checking choices was of great importance.

*"...I like to think that we do re-try because people's tastes and choices change and although maybe sometimes they can't communicate that to us doesn't mean that cause they didn't like it a year ago, doesn't mean they don't like it now..."* (Pam, Page 4, Line 8)

### Too much choice can overwhelm

The final consideration when providing choice was finding a balance between too much choice and too little. Participants had experienced the way in which too much choice had actually served to cause distress for some of the people they supported.

*"..too many choices can sometimes be too much"* (Nicola, Page 4, Line 1)

When using alternative forms of communication such as Makaton participants talked of the importance of keeping choices simple because offering all the options at once could confuse the participants and lead them to think that all the options were being offered at the same time.

*"...you couldn't say 'do you want a sandwich or do you want soup or do you want something else?' because they'd just answer 'yes'"* (Amanda, Page 2, Line 33)

### **Responsibility and risk**

In line with the theme of complications of choice was the duty of care that they have for the individuals they support. Within this theme the participants described feeling

that although choice was important they were also aware that they needed to protect them from harm. The discussions often focused on an awareness of the legislation around responsibility and human rights, for example the Deprivation of Liberty Act (2005), which was mentioned in many of the interviews.

### *Sub-themes*

#### Best interests

Responsibility was covered in a variety of different ways and often mentioned was best interests meetings where difficult decisions were made as a group thus removing responsibility from individual staff members to a team. Working for best interests was a way participants spoke about the times when choices were made without the involvement of individual service users in order to protect them from issues such as health problems.

*“What we tend to do is, if a choice is not in a best interest we go to a best interest meeting and we try not to let it get that far...” (Julie, Page 3, Line 1)*

As this quote demonstrates, best interests meetings were seen as a last resort for many of the participants who preferred to work with individuals to address potential risks.

#### Risk, vulnerability and positive risk taking

Further to the legal aspects of responsibility was a theme around the vulnerability of the people that they work with. Vulnerability was used to describe how individuals need to be protected from harm and as such their choices may be compromised. As an example Amanda spoke of the need to block access to the stairs because one service user who was physically not able to use this had injured themselves on a number of

occasions. In this situation explaining to the individual that they could not use it had not worked so the option was taken away by blocking the top of the stairs and the individual used the ramp instead. Vulnerability also extended to the idea that individuals may also be susceptible to having their choices denied. Amanda was keenly aware of the need to protect the rights of individuals to continue to express their choices and not be limited;

*“we're in a very trusted position and everybody who works here is absolutely fantastic with the clients erm but there are people out there who would take advantage of it and not be bothered... 'eat this, do this, get that done' so their shift is over and done with”*  
(Amanda, Page 4, Line 9)

There were differences between participants in the importance of protecting from risk with some arguing that there is a need to take positive risks in order to allow individuals to have as many choices as everyone else.

*“... and support them in every choice that they make even if it means taking a small risk, because we all have to take risks”* (Linda, Page 5, Line 5)

### Legislation

There was a keen awareness among participants of the relevant legislation that defined their duty of care for people with severe and profound learning disabilities. Participants spoke of the Deprivation of Liberty Act (2005) as having implications for any occasions where they could be seen to be affecting the freedom and liberties of the people they supported. Alongside this was the Human Rights Act (1998) which was also mentioned on a number of occasions contributing to an ethos within the service of protecting these rights by providing choices as much as possible. What also seemed apparent

when participants spoke of the guidelines and laws surrounding their work was a sense of insecurity about “doing it right” where they expressed concerns about whether they were acting in accordance with these rules and being aware of the possible consequences if they were not, for example losing their job.

*“You've got a lot of laws and legislations to abide by; mental capacity act, Deprivation of Liberty, lots and lots of things so you can't take somebody's choice unless it would...they'd harm themselves” (Linda, Page 5, Line 15)*

### **Enrichment and quality of life**

The theme of enrichment was common throughout all transcripts and appeared throughout the interviews. Participants spoke about ideas around enrichment as a key component of their role in working with people with learning disabilities. Ideas such as providing activities, trying new things and establishing close relationships with individuals seem to be really important to the participants in order to provide a fulfilling lifestyle for the people they worked with.

#### *Sub-themes*

##### Providing activities and opportunities

Within this sub theme participants spoke about the importance of offering a variety of different daily activities for the people they supported. The theme of activities and opportunities was universal across the participants and this seemed to be embedded in the general ethos of the services provided for people with severe and profound learning disabilities as the following quote demonstrates.



*“Activities, they're not quite important, they're very important, to get them out as much as you can on a day to day basis” (Julie, Page 1, line 22)*

At times this meant having to try lots of new things in order to see what the individuals enjoyed doing and then making a note of the things that they seemed to enjoy. Staff recognised that they needed to be creative in providing enjoyable activities for free such as indoor activities or making use of free services such as museums. The participants spoke of activities as a key part of leading as normal a life as possible and part of this was the feeling that choices should be unrestricted, that the individuals should have access to the same opportunities as everyone else.

*“Our role as a job includes support to individuals to live as much as a normal life as they can and to fulfil a healthy and normal lifestyle” (Julie, page 1, line 4)*

#### Achievement of individuals

The second sub theme was around the way the individuals they supported were able to make achievements in their daily lives. There was a strong sense of pride when individuals were able to make use of skills or engage with activities they were previously unable to enjoy. Many participants spoke of the importance of encouraging individuals to be independent and able to take care of themselves as much as possible.

*“We promote the fact that they need to do more for themselves” (Tom, Page 1, Line 13)*

#### Relationships and trust

The way participants spoke about their relationships with the people they supported there seemed a need to have real, trusting relationships, which took time to engender and develop. Participants spoke of the nature of their work as involving getting to know

the people they supported above and beyond the bare minimum. It seemed clear that participants felt a closeness with individuals making it more than just a job but *“Just like coming home”* (Tracey, Page 2, Line 17). The way in which these were relationships built upon also involved high levels of feedback which seemed really important to the participants of this study. Feedback involved laughing, smiling, appearing to be happy and enjoying themselves. This feedback seemed to give richness to the relationships between the supported and the supporters.

*“I mean like today actually seeing the client smile, make their choices erm and appear to be happy in their demeanour and their facial expressions and their body language you know it’s really nice to see...”* (Pam, Page 7, Line 22)

There were also signs that enrichment worked in two directions, with staff working towards enriching the lives of the people they support but also gaining a great personal sense of enrichment as well. This quote from Faye sums this feeling up neatly:

*“...You go home and you think ‘I did that and I made a difference there and you can’t sort of knock the smile on your face so, it’s just an ace job...”* (Faye, Page 10, Line 17)

### **Importance of knowledge and understanding**

Throughout the interviews was a consistent theme around the importance of having knowledge in the theoretical sense as well as learning skills relevant to their work.

#### *Sub-themes*

#### Training and skills

In some form, all participants spoke about the impact of training and skills to both their enjoyment of their work and also an understanding of the specific needs of the

individuals. A number of participants talked of how they had found the job difficult at first prior to having training and how knowledge and understanding had helped them to know why individuals behaved the way they did, for example Nicola talked about how difficult it was before she understood autism:

*"...before, like autism, I found it really hard to understand so before I went on the training and before I realised it was really hard"* (Nicola, Page 8, Line 14)

Tom also talked about the importance of knowledge and training in supporting people with severe and profound learning disabilities:

*"...knowledge is power, the more knowledge you have the more able and capable you are to carry out your role"* (Tom, Page 2, Line 22)

#### Planning and organisation

This theme is included within the concept of knowledge because the meaning for participants seemed to relate to an importance of gathering information about activities and planned outings in order to organise events. Participants would research the places they planned to visit to ensure that the facilities were suitable and would be able to meet the needs of the individuals.

Tom talked about how important it is to gather information about planned activities to ensure these meet the needs of individuals:

*"..what we do is if we have any kind of activity we go out, we do a reci, we make sure the place has got disability facilities..."* (Tom, Page 17, Line 13)

#### Empathy

Putting themselves in the shoes of the individuals they supported was a tool often cited by participants as a way to gain information about the best course of action. Empathy also allowed the participants to understand what it must be like for individuals with severe and profound learning disabilities who may be unable to express themselves in understandable terms.

Tom talked of how he used empathy to think about the needs of the people he worked with:

*"...you've got to be constantly thinking to yourself 'what would I want?'"* (Tom, Page 3, Line 28)

### **Person centred systems**

The fourth theme to emerge from the data was of person centred systems, which was a common approach taken by all participants. This theme was linked to the attitudes of both the staff in the residential homes and their managers. A quote from Nicola elucidates this theme neatly:

*"I'm here for him"* (Nicola, Pg 11, Line 18)

This seemed a common feeling from all the participants and gave a general sense that it was more than a job, it was about the individuals they were supporting, ensuring that the system was designed to meet their needs specifically.

### *Sub-themes*

#### Knowing the individual

Participants spoke of the need to know the individuals they worked with in order to provide a service tailored to them specifically. This was universal across all participants

where this was clearly integral to providing care for individuals with severe and profound learning disabilities. This included monitoring the likes and dislikes of individuals, which was generated often through a process of trial and error, observing the responses of individuals to various different foods, drinks and activities.

*“We have to know the group of clients to be able to do so much”* (Amanda, Page 10, Line 32)

### Adaptation and flexibility

During the interview process participants were asked about their experience in accessing choices. Participants spoke of the many different ways in which they were able to gather useful information in order to assess and interpret the preferences and needs of individuals. Finding ways to understand encapsulates not only a number of techniques such as using pictures, objects of reference and non verbal feedback but also the attitudes and dedication of the participants to 'figuring it out'. In most cases figuring it out meant the use of trial and error techniques, importantly offering as many opportunities as possible and then reviewing the response to these. After experimenting with novel ideas and getting a positive response there was a genuine sense of accomplishment. Faye described the variety of ways of accessing choice used in her work place:

*“...written communication and makaton and pointing and erm verbally spoken, it all depends what that person is communicating to us, it can be varied...”* (Faye, Page 9, Line 24)

Being person centred also involved a need to have a flexible approach and be prepared to adapt. Participants seemed to put a great deal of effort and dedication towards

adapting their way of working as well as communication methods to suit the individuals. Participants talked of the need to be flexible, not putting time pressures on individuals and generally just going “with the flow” and taking the lead of the individuals rather than pursuing their own agenda.

*“..you just go with the flow, I just go with the flow of the day that's how I am whatever comes my way..”* (Faye, Page 9, Line 1)

### Against institutions

Included within this theme was a strong commitment to avoiding any forms of institutionalisation where individuals are expected to suit the system rather than the other way around. Participants spoke of their personal experiences with institutions or stories they had heard about what these environments were like. Institutions seemed to exemplify everything the participants were working against where choice was not an option, individuals were not given a choice about when they got up, what they were to wear, what food they were going to eat. In line with a non-institutional approach participants often described their place of work as being “their home”, which seemed an important distinction from a residential home or institution as it shifted the balance of power to the individuals. Linda described the availability of choices and options within institutions:

*“They wasn't not in institutions they wasn't cause 'you will take your medication', 'you will wear this', 'you will get up' all at the same time and 'you'll sit in your room and you won't do anything', which I think is absolutely disgusting”* (Linda, Page 12, Line 26)

### Predictable environment

Being person centred also involved providing consistency and predictability in the environments of the individuals they supported. Participants described having individuals diagnosed with autism and how important having a routine is to these individuals. Staff described how it was sometimes difficult to introduce new choices due to the need to maintain these routines; however they were still able to do this in a person centred way by giving them simple choices between alternative activities on a weekly basis. Amanda explained how it had been difficult to encourage individuals to make choices because they had a particular routine, which helped them to feel less anxious. Despite this the team had been able to increase individuals' level of active choice making:

*“they do say no sometimes because they've lived in this type of setting for a few years now and are getting used to it” (Amanda, Page 3, Line 19)*

### **Frustration and stress**

The last theme clustered within the data was that of frustration and stress felt by the participants. The source of this was not identified as being from the individuals they were supporting but from systemic factors and the limitations of resources. The most common emotion generated in the interviews was that of frustration, which was related to the restrictions that participants felt were often placed on the enrichment of individual's lives.

### *Sub-themes*

#### Limitations of time and resources

The most common source of frustration regarding time and resources was from the volume of paperwork participants were required to fill in. All participants mentioned

the amount of paperwork in a negative way. There was acknowledgement of the need to have a system for monitoring to avoid possible risk of harm or abuse to the individuals but many felt that this was disproportionate. Tracey spoke of her frustration with the levels of paperwork and the limitations this put on her relationship with the people she supported:

*"I like to go in and interact with the people and sometimes you can't do that cause you're just flooded with paperwork..."* (Tracey, Page 16, Line 22)

The nature of the paperwork itself was also a source of frustration, with participants feeling that legislation put limitations on their ability to form relationships with individuals as this quote from Tom illustrates:

*"not being able to call somebody a mate or friend or not being able to pat somebody on the arm without filling in a risk assessment about it"* (Tom, Page 28, Line 20)

Participants also felt that their ability to provide choices was affected by the time it often takes to put activities in place, especially considering the shift handover during the day. Staff spoke of how resources such as money would prevent them from being able to offer as many choices as they would like to.

*"...sometimes people don't get to do all that they probably want to do because of resources..."* (Tracey, Page 7, Line 12)

Despite these restrictions and the accompanying feelings of frustration the participants were dedicated to finding ways to get around any limitations for example by looking for free activities. For example Amanda said of times when there's no money:



*"...we'll just think of what to do and a few weeks ago I took him on a bus cause he's got a bus pas and I took him to the [free] museums..."* (Amanda, Page 8, Line 5)

#### Having to say 'no'

Participants described feelings of stress about the times when they had to say 'no' to the people they supported, within this were thoughts about being unable to explain to individuals the reasons why certain options were unavailable. Having to say no was particularly difficult for participants when these choices had previously been offered since it was then even more difficult to help them to understand why the choice was no longer available. Nicola described having to say no as being particularly difficult:

*"It's hard, it's awful in a way cause you're thinking 'why can't they'"* (Nicola, Page 5, Line 31)

#### Attitudes of others

The final source of frustration for the participants came about when being confronted by other people whose attitudes were contrary to the ethos within their service. Participants talked of how difficult it can be when dealing with individuals who have their own ideas about how care should be provided and in particular when this approach was not person centred and did not encourage the individuals to develop more long term skills. Pam talked about her experiences with other staff whose work philosophy was quite different:

*"sometimes that can be frustrating when you're up against people who have negative attitudes... and they don't want to embrace change themselves"* (Pam, Page 14, Line 21)

Participants also spoke of how it can be difficult when they are not heard by people in wider systems, particularly because they know the individuals so well. Nicola talked about her experiences of not being heard by systems that made decisions about the care of the individuals she supports:

*“I think we need to be heard more, we're the ones that like work with them...it's really frustrating, makes me feel angry and I feel really sorry cause they're like, the clients, they don't understand and you're trying to fight for them”* (Nicola, Page 11, Line 5)

## **Discussion**

The current study sought to explore the experiences of people who support and care for individuals with severe and profound learning disabilities in facilitating choice. The findings show that there are a number of variables that staff consider to be very important in order to aid the process of accessing choices. It was clear from the interviews that the carers who took part were keenly aware of the value of choice for the individuals they support and were dedicated to finding ways to make this happen. Choice was embedded into the descriptions people made of their role and was described within broader frameworks of empowerment, independence and quality of life. Participants gave examples of how they had made a commitment to making choice a reality in the face of practical limitations and conflicting attitudes and it was noteworthy how similar the answers provided by participants were and how there were few contradictions between participants. The reason for such universality is unclear, however since many of the residential services were provided by the same company it is possible that the similarities were due to the training provided by these services.

The themes emerging from the data are in line with the literature which shows that choice is a complicated process for people with learning disabilities (Grove et al, 1999). The ways in which choice can be complicated were explored at length by the participants who spoke of practical limitations of time and resources as well as paying attention to the ability of individuals to make choices. Ultimately participants acknowledged that without specific verbal information choice is mostly second guessed using a variety of novel methods. The finding that choice needs to be provided in a simple way fits with the literature for people without learning disabilities, which

shows that extra cognitive effort in the process of choosing actually diminishes the positive effects of choosing and in fact can be a cause of anxiety and depression (Iyengar & Lepper, 2000). Causing confusion by offering multiple options is also not limited to individuals with learning disabilities and there is evidence in the marketing literature that offering too many options can confuse consumers with the effect that choosing becomes more difficult and less likely to occur (Chernev, 2003).

An area of complexity surrounding choice which seemed a theme in its own right was that of risk and responsibility, which was a clear concern for the participants of this study. As part of their duty of care in protecting individuals from harm participants spoke of the times when choices might be restricted. Despite this there was a leaning towards taking positive risks in order to allow individuals to experience choices more fully. The way assessment of risk affects decision making is reflected in the literature for non-learning disabled populations and shows that avoidance of unsafe or risky situations is a key concern for individuals without learning disabilities (Slovic, Fischhoff and Lichtenstein, 1984). The fact that risk assessment occurs across different groups of individuals suggests that it is not unusual that carers find themselves taking responsibility for examining risk for individuals who are perhaps less able to weigh up the consequences for themselves.

In line with positive risk taking was the theme of enrichment, which was a strong theme around providing choices and opportunities as a key element of living a 'normal life'. Participant's spoke of great lengths that they would go to in order to allow choices for the people they support and this seemed to lead to a great sense of accomplishment for them. One participant spoke of the delight that they felt when they discovered that an individual had enjoyed going to the theatre, which was

surprising to the staff who would not have expected this. This does, however point to a difficulty that seems to arise when accessing the choices of people with severe and profound learning disabilities, which is being able to think of activities that are different to what you would expect them to enjoy.

To access maximum choices and enrichment participants felt they had benefited greatly from obtaining skills and training, particularly in theoretical understanding of the needs of people with learning disabilities and autism. In line with gathering information and understanding needs, participants seemed keen to maintain a person centred environment, which meant putting individuals at the heart of their work. Staff were committed to this approach and felt that this was a key philosophical underpinning to their commitment to establishing people's choices. A repeating point throughout the interviews was a specific need to avoid forms of institutionalisation for people with learning disabilities. In describing their residential environment key terms included 'supported living' and 'their home', which echoed the beliefs that any form of institution was to be avoided at all cost. Even young participants who were not carers during the times when institutions for learning disabilities were common were passionately opposed to these places and in particular the lack of person centred care for individuals. This finding is interesting when considering that some research has suggested that deinstitutionalisation in itself has not led to the expected benefits to psychological health or behavioural problems and that the main influence on quality of life for people with learning disabilities is the involvement of professionals in their support such as psychologists and psychiatrists (Nøttestad and Linaker, 2001).

Once established that choice was important and how this was achieved as well as the specific barriers to choice participants went on to describe feelings of frustration and

stress. The most common source of these feelings was the restrictions and limitations on providing choices. Although most participants felt that choices were on the whole never impossible there were clearly times when they had to say 'no'. Being unable to provide choices in these instances often left participants feeling both guilty and frustrated.

Despite all these concerns, restrictions and a having to think and process risk and responsibility the sense of achievement that participants were able to get from making a difference in the lives of people with severe and profound learning disability seemed to keep participants focused on the individuals they supported and their role as facilitators of choice.

### *Implications*

There are several important implications that could be drawn from this study, which could benefit service development and the way carers are supported to facilitate choice for people with learning disabilities. Carers spoke of the lengthy paperwork that they were filling in and how this made fully person centred care difficult as it took too much time. A system involving more simplified forms of paperwork whilst maintaining important risk assessment would presumably therefore free up some much needed time for carers to care. Further systemic influences on the ability of carers to facilitate choice included the nature of the residential environment. Participants felt that having a small number of residents helped them to focus specifically on the individuals and thus were more able to offer choices. However although this may be an ideal situation, practically speaking offering community living arrangements with fewer residents is more costly than traditional residential care and as such may not always be a viable option (Emerson et al., 2000). Furthermore research also suggests that having a lower

staff to resident ratio actually improved measures of autonomy in community settings (Felce et al., 2000).

A second important implication of this study is the necessity of guidance and training for people supporting people with severe and profound learning disabilities. The majority of participants felt they had been fortunate with the training they had received on a regular basis. This finding was also highlighted in a study by Ford and Honnor (2000) which found that lack of knowledge and skills was a key area of concern for carers supporting people with learning disabilities. Clearly therefore offering choice depends on an awareness of specific needs of individuals and how these can be accommodated for in order to best involve people in decisions affecting their lives. Professionals working in the area of learning disabilities may find offering training in key areas a valuable resource for carers.

Finally the participants in this study identified some key ideas on how choice can best be facilitated for people with severe and profound learning disabilities. The need to keep choices fairly simple and not overpowering individuals with too many choices was one such idea and is echoed in a study by Antaki et al (2008) who identified similar factors that can lead to confusion and this adversely affect the utility of choice opportunities.

#### *Limitations of the study*

There are a number of notable limitations to the findings presented in this study. The first of these relates to the generalisability from the services interviewed to other providers of services for people with severe and profound learning disabilities. Although generalising is not an aim of IPA research it is worth noting that the people who chose

to take part in this study may not be considered representative of the entire population of carers for people with severe and profound learning disabilities. The decision to take part in this study may in fact represent something about the individuals themselves such as their attitude towards making progress through research and having opinions they wanted to express. It is noteworthy that some carers chose not to take part in this study due to time restraints and it is worth considering how different the data might have been for these individuals.

The second limitation of this study is similar to the first in that the participants who took part supported a maximum of 9 individuals, the lowest being 2. The participants therefore were mostly working within an arrangement akin to supported living rather than residential homes and it is possible that this affected their ability to provide choices and again this may not be representative of other residential settings where the ratio of staff to service users is larger.

Finally, this research focused largely on small scale everyday levels of choice and it was regretful that it was not possible to cover choice regarding broader issues such as where to live, who to live with and with whom to have relationships.

#### *Future research*

Given the limitations and restrictions upon this project there are a number of possible avenues for further research to explore. Gaining access to other groups of carers would be a particularly useful study in order to address the issues involving having enough time to take part in research and providing care and support to a larger group of individuals. The participants of this study were able to find the time to take part and therefore it would be helpful to explore differences for carers who do not have the



time to take part. Carers who support larger groups of individuals may have less time to get to know people and it would be interesting to find out how choice may be facilitated in these situations.

The focus on small level choices such as food and clothes could easily be addressed by exploring how staff are able to facilitate choice in different domains such as where individuals live and who with. This would enable an understanding of ways in which choice might be limited due to the restrictions on resources such as accommodation and would open up the possibility of exploring how carers might facilitate choice in such circumstances.

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**Author Guidelines****1. GENERAL**

The *Journal of Applied Research in Intellectual Disabilities* is an international, peer-reviewed journal which draws together findings derived from original applied research in intellectual disabilities. The journal is an important forum for the dissemination of ideas to promote valued lifestyles for people with intellectual disabilities. It reports on research from the UK and overseas by authors from all relevant professional disciplines. It is aimed at an international, multi-disciplinary readership.

The topics it covers include community living, quality of life, challenging behaviour, communication, sexuality, medication, ageing, supported employment, family issues, mental health, physical health, autism, economic issues, social networks, staff stress, staff training, epidemiology and service provision. Theoretical papers are also considered provided the implications for therapeutic action or enhancing quality of life are clear. Both quantitative and qualitative methodologies are welcomed. All original and review articles continue to undergo a rigorous, peer-refereeing process.

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**2. ETHICAL GUIDELINES**

The *Journal of Applied Research in Intellectual Disabilities* adheres to the below ethical guidelines for publication and research.

**2.1 Authorship and Acknowledgements**

**Authorship:** Authors submitting a paper do so on the understanding that the manuscript has been read and approved by all authors and that all authors agree to the submission of the manuscript to the journal. ALL named authors must have made an active contribution to the conception and design and/or analysis and interpretation of the data and/or the drafting of the paper and ALL authors must have critically reviewed its content and have approved the final version submitted for publication. Participation solely in the acquisition of funding or the

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- Use a tab, not spaces, to separate data points in tables.
- If you use a table editor function, ensure that each data point is contained within a unique cell, i.e. do not use carriage returns within cells.

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The reference list should be in alphabetic order thus:

- Emerson E. (1995) *Challenging Behaviour: Analysis and Intervention in People with Learning Disabilities*. Cambridge University Press, Cambridge.
- McGill P. & Toogood A. (1993) Organising community placements. In: *Severe Learning Disabilities and Challenging Behaviours: Designing High Quality Services* (Eds E. Emerson, P. McGill & J. Mansell), pp. 232-259. Chapman and Hall, London.
- Qureshi H. & Alborz A. (1992) Epidemiology of challenging behaviour. *Mental Handicap Research* 5, 130-145

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**Appendix 2. Data extraction form**

Study number	Title	Author	Year	Journal	Methodology	Findings

**Appendix 3. Quality assessment table**

Criterion	Score			
1. An explicit theoretical framework and/or literature review	1	2	3	4
2. Aims and objectives clearly stated	1	2	3	4
3. A clear description of context	1	2	3	4
4. A clear description of the sample and how it was recruited.	1	2	3	4
5. A clear description of methods used to collect and analyse data.	1	2	3	4
6. Attempts made to establish the reliability or validity of data analysis	1	2	3	4
7. Inclusion of sufficient original data to mediate between evidence and interpretation	1	2	3	4
<b>Key</b>				
4 - Excellent	3- Good	2 - OK	1 - Poor	

**Appendix 4. Quality scores**

<b>Study</b>	<b>Total quality score</b>
1	24
2	22
3	25
4	27
5	24
6	23
7	24
8	15
9	25
10	24
11	26
12	23
13	25
14	28
15	26
16	18
17	21
18	24
19	22
20	25
21	27

## **Appendix 5. Ethical approval**

## Appendix 6. Participant information sheet

### Participant information sheet

We would like to invite you to take part in a research study. Before you decide you need to understand why the research is being done and what it would involve for you. Please take time to read the following information carefully.

#### Who is organising this research?

This research is being carried out as part of my doctoral qualification in clinical psychology at the University of Hull. The study has been assessed by the Ethics committee of the Post-Graduate Medical Institute at the University and was given a favourable opinion. This means that the study has been checked to make sure it will be conducted appropriately and ethically.

#### What is the purpose of the study?

This study looks at choice making for people with severe or profound learning disabilities. With the difficulties some people have in communicating their preferences it becomes especially important to look at how choices are facilitated by others. For people with severe or profound learning disabilities choice would most likely be facilitated by the carers who work with them. This study is aimed at understanding the experiences of those caring for people with a severe or profound learning disability in encouraging choice.

#### Why have I been invited?

As a carer working in a residential home for people with severe or profound learning disabilities you have been asked to share your experiences of supporting choice for the people you work with.

#### Do I have to take part?

It is up to you to decide. The study will be described to you in this information sheet which details what the study will involve. More information has been provided to the manager of your residential home which contains a poster explaining why the study is being carried out. If you decide you would like to take part you will be given a reply slip to express your interest.

#### What will happen to me if I take part?

- Firstly you will be asked to sign a consent form to show you have agreed to take part. As explained in this form you are free to withdraw from the study at any time, without giving a reason.
- The main study is in two parts; firstly you will be interviewed by the researcher for approximately an hour about your experiences of supporting choice. This interview will be audio taped to be transcribed later – when the study is finished these will be destroyed. Secondly, you will be asked to fill out a questionnaire about general information about yourself and the home you work in.



- You will only be asked to attend this one session, however you may be asked to attend a second session at a later date during which you will be asked questions about the accuracy of the summary of the information you gave during the interview.
- Personal information such as names will not be taken at any time and recordings of the interviews will be securely stored and only accessed by the researcher or research supervisor. Transcripts from the interview may be read by members of a discussion group who will be commenting on themes that arise from the data.

**What happens to the findings of the study?**

The study will be written up and submitted as part of my doctoral qualification. The final write up may also be published in an academic journal where others will be able to read the findings. Personal quotes given in the interview may be used to give readers an idea of carer's views; however, there will be no details used that would mean individual participants could be identified.

**Further information and contact details**

More detailed information about this study can be obtained directly from the researcher using the details below. If you are unhappy with the study you should contact myself as the main researcher and my details are provided below. I am supervised by Paul Duggan, Chrissie Blackburn and Nick Hutchinson who you may have already been in contact with.

**Contact details of main researcher: Jennifer Bradley****Email:**

j.bradley@2004.hull.ac.uk

**Phone:**

07817118201

**Address:**

Department of Clinical Psychology and Psychological Therapies  
University of Hull  
Hertford Building  
Cottingham Road  
Hull  
HU6 7RX

**Appendix 7. Consent form**

Centre Number: University of Hull

Participant Identification Number for this study:



**CONSENT FORM**

**Title of Project:** “What is the experience of carers in facilitating choice for people with a severe or profound learning disability?”

**Name of Researcher:** Jennifer Bradley (Trainee clinical psychologist)

Please initial box

- 1. I confirm that I have read and understand the information sheet for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.
- 3. I agree to take part in the above study.


\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Name researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

**Appendix 8. Interview schedule**

<b>Question</b>	<b>Prompt</b>
<b>The client group</b>	
How would you describe your role with people who have severe & profound learning disabilities?	What kinds of tasks does your job involve?
What is it like for you working with people who have severe & profound learning disabilities?	
<b>Choice</b>	
What comes to mind when thinking about choice?	
In your personal life what does choice mean to you?	
How important is choice to you?	In what way?
<b>Choice and Learning disabilities</b>	
In your day to day work, what sorts of choices/decisions do you help people with severe & profound Learning Disabilities to make?	
What does choice/ choosing mean to the people you work with?	1. Thinking generally, do you think choice is important to consider for people with complex needs? 2. In what way?
What do you think about the ability of the people you work with to make choices?	What kinds of factors do you think affect the ability of people with complex needs to make choices?
<b>Facilitating choice</b>	
What is it like for you on a day to day basis supporting people with sev/prof ld to make choices	What makes it easier? What makes it more difficult? Can you give me some examples of times when it is easier or more difficult
What is it like for you to access the choices of the people you work with?	When people need to make a decision how does this affect you?
Is there anything that would make it easier for you to encourage individuals to make their own choices?	What might be done differently in the place you work so that people can express their choice?
We have covered quite a lot, is there anything else we need to cover?	Is there anything you would like to say about your experiences?
Was there anything you expected us to talk about that we didn't?	Do you have any questions?

**Appendix 9. Demographic questionnaire**

**Background information**

Female  Male

Age \_\_\_\_\_

**Job information**

**Place of work (Please tick one box)**

Residential private	<input type="checkbox"/>
Residential Local authority	<input type="checkbox"/>
Residential voluntary/ charity organisation	<input type="checkbox"/>
Other (please specify)	<input type="checkbox"/>

**Experience**

How many months or years have you worked as a carer for people with Learning Disabilities?

How many months or years have you worked in your current job?

**Type of experience in Learning Disabilities:**

How much experience have you had working with people with mild to moderate learning disabilities? (Please circle)

<b>None at all</b>		<b>Some</b>		<b>A lot</b>
1	2	3	4	5

How much experience have you had working with people with severe and profound learning disabilities? (Please circle)

<b>None at all</b>		<b>Some</b>		<b>A lot</b>
1	2	3	4	5

Do you have past experience with other client groups (for example, older adults)?

Yes

No

If yes, please specify

Hours of work

Full time

Part time

Have you had any training in the past 2 years which included the topic choice? (please tick one box)

Yes

No

If yes, please specify

**Information about the residential setting in which you work**

How many people live there?

What is the age range of the people who live there?

How many staff work there (approximately)

**Information about the residents**

To your knowledge how many of the residents you work with have the following additional needs? (please tick one box)

Additional need	None	Some (below half)	Most (Over half)	All
Epilepsy	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Hearing difficulties	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Vision impairment				
Physical disabilities (for example, motor impairment, cerebral palsy, mobility problems)				
Communication difficulties (speech impairment)				
Autistic spectrum disorders (for example, Autism, Aspergers syndrome)				
Challenging behaviour (for example, aggression to self or others, destructive behaviours, inappropriate sexual behaviour)				

## Appendix 10. Example IPA transcript

Stage one: reading, re-reading, initial note taking and summarising

J	OK, and when you know when people are having to make a decision or they're trying to choose and you're helping them to do that, how do you think that affects you personally, If you're there trying to help them?	
P	erm... its hard to think cause you're never thinking about yourself while you're here (laughs) erm... I mean you can't if, again for instance, if you're giving them the choice to go out for the day getting shoes, coat and a bag, at home I'd grab my keys and be gone, half an hour later you can still be there encouraging them to put their coat on	Taking time Not thinking about me
J	hmm	
P	put their arm into their coat and you're thinking oh come on we could already be out, we could be doing this, we could be doing... but again that is not their fault and you've got to clear your mind and say 'right, one step at a time, put your arm in your coat' and that's it, do it at their pace as well	Letting go Pacing the time Clearing my mind
J	so you have to give time to..	
P	and that's it and that's where again you think you want to go out with them for the day you know make sure you're up early and then say 'right, where would you like to go today?' but then you're thinking, right we've got to be back for change over at 3 o clock	Thinking and planning Giving lots of time
J	hmm	
P	and that's always, I think that's the stressful part for me, its not providing the choices and following them through and if they change their mind or whatever, because of the setting we're in time's always against you	Time, resources Stress – not providing choice
J	yeah	
P	which doesn't help them because obviously they have, things can't be rushed	Taking time, don't rush
J	yeah	
P	yeah	
J	so you've got your own-	
P	and if one of them is getting ready for a party but he wants to wash his face twelve times, you sit and let him wash his face twelve times, if you're half an hour late for the party its still a big achievement of getting ready and going to the party	Relaxing Letting go Being flexible
J	hmm	
P	even if he's there for five minutes, half an hour, you've just got to roll with it (laughs)	Roll with it

## Stage two: Generating sub-themes

J	OK, and when you know when people are having to make a decision or they're trying to choose and you're helping them to do that, how do you think that affects you personally, if you're there trying to help them?		
P	erm... its hard to think cause you're never thinking about yourself while you're here (laughs) erm... I mean you can't if, again for instance, if you're giving them the choice to go out for the day getting shoes, coat and a bag, at home I'd grab my keys and be gone, half an hour later you can still be there encouraging them to put their coat on	Taking time Not thinking about me	Time resources Focus on the individual
J	hmm		
P	put their arm into their coat and you're thinking oh come on we could already be out, we could be doing this, we could be doing... but again that is not their fault and you've got to clear your mind and say 'right, one step at a time, put your arm in your coat' and that's it, do it at their pace as well	Letting go Pacing the time Clearing my mind	Flexibility Adaptation
J	so you have to give time to..		
P	and that's it and that's where again you think you want to go out with them for the day you know make sure you're up early and then say 'right, where would you like to go today?' but then you're thinking, right we've got to be back for change over at 3 o'clock	Thinking and planning Giving lots of time	Planning and organising
J	hmm		
P	and that's always, I think that's the stressful part for me, its not providing the choices and following them through and if they change their mind or whatever, because of the setting we're in time's always against you	Time, resources Stress – not providing choice	Limitations of time Stress
J	yeah		
P	which doesn't help them because obviously they have, things can't be rushed	Taking time, don't rush	Flexibility
J	yeah		
P	yeah		
J	so you've got your own-		
P	and if one of them is getting ready for a party but he wants to wash his face twelve times, you sit and let him wash his face twelve times, if you're half an hour late for the party its still a big achievement of getting ready and going to the party	Relaxing Letting go Being flexible	Flexibility Focus on achievements
J	hmm		
P	even if he's there for five minutes, half an hour, you've just got to roll with it (laughs)	Roll with it	Flexibility



## Stage three: Pulling together sub themes and super ordinate themes

<b>Super-ordinate theme</b>	<b>Sub-theme</b>	<b>Example quote</b>
<i>Importance of knowledge and understanding</i>	Planning and organising	<i>"you know make sure you're up early and then say 'right, where would you like to go today?'"</i> Page 21, line 6
<i>Person – centred systems</i>	Flexibility	<i>"that's it, do it at their pace as well"</i> Page 21, line 4
	Adaptation	<i>"you've got to clear your mind and say 'right, one step at a time, put your arm in your coat'"</i> page 21, line 2
<i>Frustration and stress</i>	Stress – not providing choice	<i>"that's the stressful part for me, its not providing the choices and following them through"</i> page 21, line 12
	Limitations of resources	<i>"because of the setting we're in time's always against you"</i> page 21, line 15

## **Appendix 11. Reflective statement**

### **Reflective statement**

Before I began my research project I always thought I would prefer to carry out a quantitative study rather than a qualitative one, believing that this would be more rigorous and therefore more valuable. However along the way I have learnt a great deal about the values of using qualitative methods and the richness of the data that comes with it. I have been genuinely curious about the lives of the people that were part of my study and those of the people they supported. I was touched by the warmth of many of the people that I saw and I thoroughly believe this warmth and compassion could not have been explored using a method other than qualitative.

The process of doing the research has been both tiring and enjoyable at different times. I was surprised at how much I immersed myself in the process and started to feel that there was a great benefit to the work I was doing. In particular the people that I interviewed had a chance to be heard and have their opinions valued, which seemed to be a useful process for them and me.

There were strengths and limitations to the research process and in particular it would have been helpful to have found ways to pursue different groups of carers. Given that some participants were willing to take part in the project I did not put in extra energy to pursue individuals who felt their time was limited and so chose not to take part. Looking back it would have also been helpful to have had time to go back and check the quality of the data analysis by speaking to the participants. The time taken doing the transcriptions meant that towards the end of the project there was no time to do this extra quality check, this would have added more meaning to the themes generated and it was therefore regretful that this was not possible. If I had the opportunity to make changes to the interview process I would have been more probing about the contradictions that seemed to be occurring between the different

questions. The process of challenging some of these contradictions would have helped to acknowledge and understand some of the complications involved in providing choice for people with severe and profound learning disabilities as well as encouraging participants to reflect on the basis of these contradictions. Further to this, if I could alter the interview schedule I would include some queries about the larger levels of choice and would have asked participants to think about how they would facilitate these choices and how this might be different to everyday choices such as food.

The project did have a number of positives including broadening the current literature to include the experiences of those who are crucially involved in facilitating choices. The literature currently involves no exploration of how carers facilitate choice and how therefore this might be made possible for other services for people with learning disabilities. Another strength of the project design was that using a flexible semi structured interview allowed carers to explore areas that are meaningful to them and many of the participants did use this time to voice their concerns. A quantitative approach may have missed some of the more subtle aspects of choice such as the specific complications involved in a population using different forms of communication.

If I were to give advice to anyone thinking about taking up a project like mine I would say that they should give themselves plenty of time to write the transcriptions. I knew it would take a long time and it took even longer than this, which really does drain the time to conduct the analysis. There was a great benefit to conducting the transcriptions myself as I felt I got to know the data really well and this made the analysis part much easier. Other advice I would give would be to make sure that you don't lose sight of what's important when doing research, the process can be fun and it's a great opportunity to learn new and very different skills. I have enjoyed this project immensely and although at times it felt like an up-hill battle this was outweighed by the thrill of doing something important and getting to know people's stories.

I cannot underestimate the importance of support that I know has gotten me through this project. Having someone who can be there when it feels really tough to help you keep going and having a supervisor who is willing to be there for you at every turn has made a massive difference to my work. There were times when I kept struggling on my own and completely forgetting to ask for help and when I did it was like being sat in the dark and having the lights turned on! It seems so important not to try to do this by yourself as much as possible and allowing yourself to be a learner in the process teaches you as much as reading a book.

My thoughts are now focused on what will happen next; I really want to think that I will be able to conduct research in the future but I recognise that a lot of clinicians don't find the time to do this. I hope that my future self will read this and remember the sense of accomplishment and great value that I got from it and that this will inspire her to find the time to once again get immersed in stories.