

Exploring person-centred support in
adults with intellectual disabilities and
challenging behaviour supported by
paid carers in the community

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Doctor of Philosophy (PhD)**

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

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Preface

In this thesis I explore the nature of person-centred support provided to adults with intellectual disabilities (ID) and challenging behaviour living in the community and supported by paid carers, using a multiple methods approach.

The first chapter provides an overview of the care trends for people with ID over the last few decades and discusses the results of a systematic review of the effectiveness of person-centred planning (PCP) for this population group. The findings are discussed within the context of the present project and the research questions of the thesis are presented.

The second chapter provides a broad overview of the constructs that are central to the rest of the thesis i.e. challenging behaviour, person-centred support and choice.

The third chapter addresses the question of measuring person-centred support. A search for holistic non-observational quantitative measures of person-centred support specific to people with ID did not find any and therefore the search was expanded to include measures used in other populations i.e. older adults with dementia. Two measures were chosen and their suitability tested in the sample of the present project. An additional measure of choice availability, which has been previously used in research with people with ID, was also adapted for use in the sample of this thesis.

In the fourth chapter person-centred support is explored in relation to other variables in a cross-sectional study which was conducted within the context of a wider multi-centre randomised controlled trial investigating the effectiveness of Positive Behaviour Support (PBS) delivered by health professionals for the reduction of challenging behaviour in people with ID. I worked as a full time research assistant on the PBS study and was involved in the data collection from baseline to final follow-up. Data

collected for the purpose of the cross-sectional study includes both data collected during the PBS study as well as data collected by myself specifically for the PhD.

The fifth chapter presents the findings from naturalistic observations in the living environments of people with ID. The aim of the study was to provide a snapshot of the support that individuals receive when they are at home and, where possible, to gain a better understanding of the circumstances which may lead to individuals' challenging behaviour. The observations provide an attempt to answer the questions "What does support look like?"; "Can extrapolations be made as to what constitutes good or bad support?" and "How does it fit with person-centeredness?" Whilst the cross-sectional study provides carers' self-report responses of person-centred support which may be subject to desirability bias, the observations provide a way to triangulate those findings and draw possible comparisons.

In the final chapter I summarise the findings from the studies and discuss potential practice implications and directions for future research.

Researcher's contribution

I completed the work for this thesis as a part-time PhD student whilst working as a full-time research assistant on the above mentioned PBS study. I contributed to the data collection of the PBS study from baseline to final follow-up, at which point I was the only research assistant and completed all study assessments. Follow-up data from assessments completed by paid carers in the PBS study was used in the present project. I was fully responsible for recruitment and data collection for the additional questionnaires which were not part of PBS study assessment (person-centred support and choice measures). Although I sought advice from methodologists, e.g. statisticians, within the department I conducted all the data analyses for all studies included in this thesis.

I led the work of the systematic review including the literature searches, data extraction and quality appraisal of the included studies, with support from a second reviewer for inter-rater reliability exercises.

I also took full responsibility for the observational study, including the following tasks: preparation of materials and application to NHS ethics committee; recruitment of participants, data collection, data entry, cleaning and analysis.

During the course of my PhD study I wrote two papers which have been published in peer reviewed journals and presented my work at various conferences and seminars in the UK and internationally.

Acknowledgments

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I would also like to give a special thank you to my colleague Dr Michaela Poppe who has worked alongside me during the last four years and she has been there to support me and encourage me from the very start. A special thanks also goes to Dr Katrina Scior who gave me invaluable feedback and guidance during the PhD upgrade viva and on the multiple occasions when I presented my work at the University College London Centre for Developmental Disabilities Research seminars.

I express my gratitude to Brendan Leahy and the service-users representatives of Camden SURGE at The Advocacy Project who have given me invaluable advice throughout the whole project and I am very grateful for the funding provided by the Scottish Institute of Education Trust which has helped me cover some of the cost of my PhD tuition fees.

Not least of all, I would like to thank all the participants who took part in the study as without them this work would have not been possible.

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Abstract

Background

Deinstitutionalisation and the movement of people with intellectual disabilities (ID) to the community have seen the emergence of care philosophies aimed at tailoring services to individuals' needs. Person-centred support has been widely advocated and considered synonymous of good care. It is useful to investigate if day-to-day support provided by paid carers in the community is person-centred.

Aims

1. To explore person-centred support and choice in adults with ID and challenging behaviour.
2. To investigate correlates of person-centred support, including challenging behaviour.
3. To investigate whether the results of self-report questionnaires and direct-observations are comparable.

Methods

1. Self-report measures of person-centred support typically used by staff supporting older adults with dementia were adapted for use by staff supporting adults with ID and challenging behaviour. A measure of choice availability was also updated.
2. A cross-sectional study of 109 paid carers supporting adults with mild to severe ID was conducted to address aims 1 and 2.
3. Naturalistic observations of eighteen participants with ID were conducted to complement the results of the cross-sectional study. Data was collected using momentary time-sampling and narrative descriptions.

Results

Paid carers reported high levels of person-centred support and choice availability for service-users.

No significant associations were found between person-centred support and characteristics of the living environments, however choice availability was significantly higher in supported living compared to residential care homes and in living environments with fewer residents. Carers who reported higher levels of person-centred support experienced less subjective burden in their jobs. There was an association between choice and service-users' adaptive behaviour. No association was found between person-centred support/choice and global challenging behaviour; stereotyped behaviour however was negatively associated with autonomy and carers' knowledge of individuals with ID.

The findings from the observations showed lower levels of person-centred support than those reported by paid carers, suggesting desirability effects in carers' responses. Low levels of engagement in meaningful activities, assistance and contact from staff were observed, although there was much variability at the individual level. There were few instances of challenging behaviours and these mostly consisted of stereotyped/repetitive movements which were prevalent in disengaged participants.

Implications

The support for people with ID and challenging behaviour requires improvement but quality evaluation criteria adopted by inspectors and regulators may need to be reconsidered.

Improvements in day-to-day support could reduce stereotyped behaviour but input from skilled professionals may be required for other types of challenging behaviour.

Chapter 1. Introduction and systematic review of the effectiveness of person-centred planning for people with intellectual disabilities

Section 1A General introduction: intellectual disabilities, care and person-centred planning

Definition of Intellectual Disability

The Diagnostic and Statistical Manual of Mental Disorders version 5 (American Psychiatric Association, 2013) describes intellectual disability (intellectual developmental disorder) as an impairment of general mental abilities that affect adaptive functioning in the following domains:

- Conceptual (knowledge, language, memory, maths reasoning, reading, writing)
- Social (empathy, social judgement, interpersonal communication skills, ability to make and retain friendships)
- Practical (self-management in areas such as personal care, money management, task organisation).

In order for a diagnosis of intellectual disability (ID) to be given, the person's symptoms must have started during the developmental period. The disorder is considered chronic and symptoms are known to persist through to adulthood.

These diagnostic criteria had also been used in the UK Government's 2001 White Paper *Valuing People* which used the following definition to describe an ID:

'ID includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;
- a reduced ability to cope independently (impaired social functioning);
- which started before adulthood, with a lasting effect on development’.

This definition is also consistent with that adopted by the World Health Organisation’s International Classification of Diseases (ICD-10, 2010), however a further characteristic which has often been incorporated in the definition of ID is an intelligence quotient (IQ) of at least two standard deviations below the population average (IQ < 70) (O’Brien, 2006).

The term typically used in the United Kingdom is learning disability and it is used interchangeably with the terms ID and intellectual impairment. Other countries such as the USA may use other terms to describe ID, such as mental handicap or the outdated term mental retardation. In this thesis the term intellectual disability will be used throughout.

People with an ID also tend to have a range of physical difficulties which are usually more pronounced in people with more severe intellectual impairment (Emerson & Einfeld, 2011). Emerson and Einfeld (2011) distinguish between people with a mild intellectual impairment who fall at the lower end of the normal distribution of intelligence in the general population and those with more severe intellectual impairment which present a ‘general deficit in cognitive functioning’ and are also more likely to present further problems such as sensory and motor deficits, neurological problems and communication impairments. Table 1.1 describes the various classifications of ID based on IQ scores.

Table 1.1. Classification of intellectual disabilities according to IQ score

Degree of ID	IQ score
Mild	50-55 to ~70
Moderate	35-40 to 50-55
Severe	20-25 to 35-40
Profound	<20-25

In a meta-analysis conducted by Maulik, Mascarenhas, Mathers, Dua, & Saxena (2011) it was calculated that the overall prevalence of ID in the general population is around 1%; O'Brien (2006) reported estimates that 2.5% of the general population have a mild intellectual disability and that approximately 0.4% have a moderate to profound ID and a similar prevalence rate (2.7%) was given in a recent report by Public Health England (Learning Disabilities Observatory, 2016). Due to population increases, increased survival rates among people with more complex disabilities and reduced mortality, Emerson and Hatton (2008) proposed that the prevalence of people with ID in the UK is on the increase and this is likely to be sustained.

The transformation of care for people with intellectual disabilities

In recent years there has been a great emphasis on the need to provide better care for people with ID. In 2011 the BBC Panorama 'Undercover Care: The Abuse Exposed' revealed how a group of people with ID and challenging behaviour residing at Winterbourne View Hospital were on the receiving end of disturbing abuse and neglect by those who were supposed to provide care and support. The documentary highlighted how all too often people with ID do not receive good quality care, and although good services do exist, too many people receive sub-standard care. As a response to the Winterbourne View scandal, and to other calls for change such as the Mansell Report (Department of Health, 2007b), The Department of Health (DOH) called for an urgent transformation of the provision of care nationwide and in its review *Transforming care: A National response to Winterbourne View Hospital* it called for a

widespread improvement of care and safety for vulnerable people such as individuals with ID (Department of Health, 2012).

The transformation process however is not entirely new and it has already been ongoing for the past few decades. In reflection to publications such as *Better Services for the Mentally Handicapped* (Department of Health and Social Security, 1971), the NHS and Community Care Act (1990) and *Valuing People* (Department of Health, 2001), service delivery has progressively been shifting from a system-centred approach to a person-centred approach, tailoring services around individuals, rather than enforcing *one size fits all* structures (Kaehne & Beyer, 2014). People with ID have increasingly been moving from large institutions to smaller community staffed housing settings with fewer residents and higher staffing ratios, where it is believed they can benefit from richer home-like environments and better care provision which enables people to achieve a better and more ordinary quality of life, comparable to that of people without a disability (Felce & Perry, 1995b, 1995a; Mansell & Beadle-Brown, 2004c). It is important to note, however, that there are still approximately 2600 people with ID living in inpatient settings (Health and Social Care Information Centre, 2016).

The process of deinstitutionalisation has been accompanied by new service philosophies which place a greater emphasis on person-centred support and enhancement of individualisation in the provision of services (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004). Person-Centred Planning (PCP) has been widely acclaimed as a means to achieve individualised support for people with ID and improving their quality of life; it has often been associated with the inclusion agenda which strives to achieve the same opportunities for people with ID as the rest of the population and underlines the importance of equality and empowerment (Bollard, 2009). The principles of PCP are now embedded within agency policy and government regulations in countries such as the UK (Department of Health, 2009), US and Australia (Holburn et al., 2004).

Person-Centred Planning

PCP is a multi-component complex intervention which has the potential to impact on a range of different outcomes relevant to an individual's quality of life, encompassing principles and values which strive to move away from a culture of dependency and seek to promote the realisation of each individual's potential. However, it is not a standardised intervention, but an umbrella term which is often used to describe approaches and techniques that share common characteristics. Although these approaches may differ in their practical application, according to the context and purpose for which they are adopted, their underlying aim is the same, and it is generally agreed that the common denominator between the variations of PCP is to support people with ID to build a lifestyle based on choices, preferences, shared power, rights and inclusion (Klatt et al., 2002)

PCP places great emphasis on individualised support plans for each care-recipient which are aimed at improving the quality of life of each individual. Each individualised support plan is aimed at setting and meeting goals for each individual in relation to activities, skills acquisitions, participation in the community and development of social relationship (Claes, Van Hove, Vandevælde, van Loon, & Schalock, 2010). Sanderson (2000) described five key features of PCP: (a) the person is at the centre, (b) family members and friends are partners in planning, (c) the plan reflects what is important to the person, his/her capacities and what support he/she requires, (d) the plan results in actions that are about life, not just services and reflect what is possible and not what is available, (e) the plan results in ongoing listening, learning and further action.

In PCP power is shifted from staff and stakeholders to individuals and their families, setting it apart from traditional approaches such as Individual Personal Planning and Individual Habilitation where individuals are passive recipients of care and professionals make decisions and plans *for* them. In PCP decision-making is driven by the individuals themselves and by those who care about them, with particular emphasis

on self-determination, choice and autonomy. It is a crucial aspect of PCP that the person with an ID and his/her support network play a primary role in the planning process which is driven by the person's skills and abilities rather than their deficits and impairments (Sanderson, 2000). Examples of formalised PCP approaches include Essential Lifestyle Planning (Smull & Harrison, 1992), Personal Futures Planning (Mount, 1987), Planning Alternative Tomorrows with Hope (PATH) (Pearpoint, O'Brien & Forest, 1991) and the McGill Action Planning System (MAPS) (Vandercook & York, 1989); Sanderson (2000) summarises the applications and differences between the approaches.

Despite the emphasis on PCP as the cornerstone of care, there is scarce research that has formally evaluated its effectiveness in promoting the quality of life of people with ID. Research appears to mainly consist of anecdotal reports, descriptive case studies or studies subject to significant bias, making it difficult to draw conclusions regarding its impact.

In an initial systematic review of evidence for Essential Lifestyle Planning, Rudkin and Rowe (1999) found five studies with a total of 108 participants which reported data on outcomes of PCP. The authors concluded that "there is no quantitative evidence to support the use of lifestyle planning in general or in any individual form" (p.366), as they found no significant difference in outcomes for those with a person-centred plan compared to other approaches. In a subsequent systematic review of the effectiveness of PCP, Claes et al. (2010) found that, although the evidence base was growing, it was still scant and only limited generalisations could be drawn from the findings. Their literature search was limited to articles published on the Web of Science between 1985 and 2009 and the review included studies which combined PCP with other approaches such as Positive Behaviour Support or aspects of it such as functional analysis (Artesani & Mallar, 1998; Buschbacher, 2004; Buschbacher & Fox, 2003; Gardner, Bird, Maguire, Carreiro, & Abenaim, 2003; Kennedy et al., 2001). Without a specific

approach to the development and evaluation of psychosocial multi-component interventions, however, the message about effectiveness remains unclear.

Following the search period covered by Claes et al. (2010) new policy recommendations and guidelines have been published in various countries which advocate the use of PCP: in the UK PCP has been included in various policy initiatives particularly as a call to transforming care for people with ID (Department of Health, 2009; NICE, 2015); in Australia The 2010-2020 Disability Strategy (COAG, 2011) has called for PCP to be included in new policy directions and in the USA the Centres for Medicare and Medicaid services have promulgated regulations mandating PCP (CMS, 2014). It would therefore be useful to know whether a greater evidence-base has been generated in favour of PCP following the publication of such policies. The next section presents the results of a systematic review investigating the effectiveness of PCP.

Section 1B Systematic Review

(See Appendix A1 for the published version of the review covering the period until May 2014. A comprehensive and updated version is presented in this chapter)

Aims and objectives of the review

The present review seeks to build on previous work to provide an up-to-date synthesis of the evidence base pertaining to PCP as a standalone intervention and summarise the impact of PCP on people with ID. The objectives are as follows:

1. To provide an updated review of the status of research concerning the effectiveness of PCP on outcomes for people with ID,
2. To determine whether PCP and its components are effective in improving outcomes for people with ID,
3. To determine what outcomes are most likely to be affected by PCP,
4. To identify directions for future research.

Method

Search strategy

The literature search was conducted in two phases. In the first phase the electronic databases PsycInfo, Embase, CINHALL, PubMed, Web of Science, Scopus and Medline were searched for studies covering the period from January 1990 to May 2014 using search terms related to ID in combination with terms related to PCP (Ratti et al., 2016); Since PCP includes a variety of approaches which use different terminology, a wide range of terms was used in order to capture all relevant studies (e.g. PCP, personalisation, shared action planning; see Appendix A2 for a full list of terms). Electronic searches were supplemented by the ancestry method (hand-searching the references of all included studies to identify any further relevant papers; Polit & Beck, 2014). In order to provide an up to date review, a subsequent search (phase 2)

covering the period from 2014 to May 2017 was also conducted however only the terms “person-centred planning” and disab* were used.

Inclusion and Exclusion Criteria

- Population: studies were included if participants had an author defined ID or an IQ below 70.
- Study design: studies were included if their primary aim was to evaluate the effects of PCP on outcomes for individuals with ID and either qualitative or quantitative data were available. Retrospective case-note studies and prospective follow-up studies were included. Studies were excluded if they evaluated the implementation or processes of PCP but reported no data on the impact of PCP on individuals; if studies only reported process variables such as improved knowledge following training, these were excluded. Studies were also excluded if the main aim of the study was the evaluation of a combination of approaches (e.g. PCP and Positive Behaviour Support). Studies which were purely descriptive and those which reported outcomes of author defined traditional planning approaches such as Individual Personal Planning and Individual Habilitation were also excluded. No studies were excluded based on the number of participants.
- Setting: No studies were excluded on the basis of the country or setting in which PCP took place. Settings varied from group homes in the community to in-patient settings, and all were considered.
- Publication: All studies found using English search terms irrespective of publication source were considered.

Outcomes

Primary outcomes which were expected to be influenced by PCP, based on knowledge of the literature and experience in the field, were:

- Quality of Life and Life Satisfaction
- Choice and Self-Determination
- Participation in activities
- Inclusion

Secondary expected outcomes were behaviour, adaptive functioning employment and health.

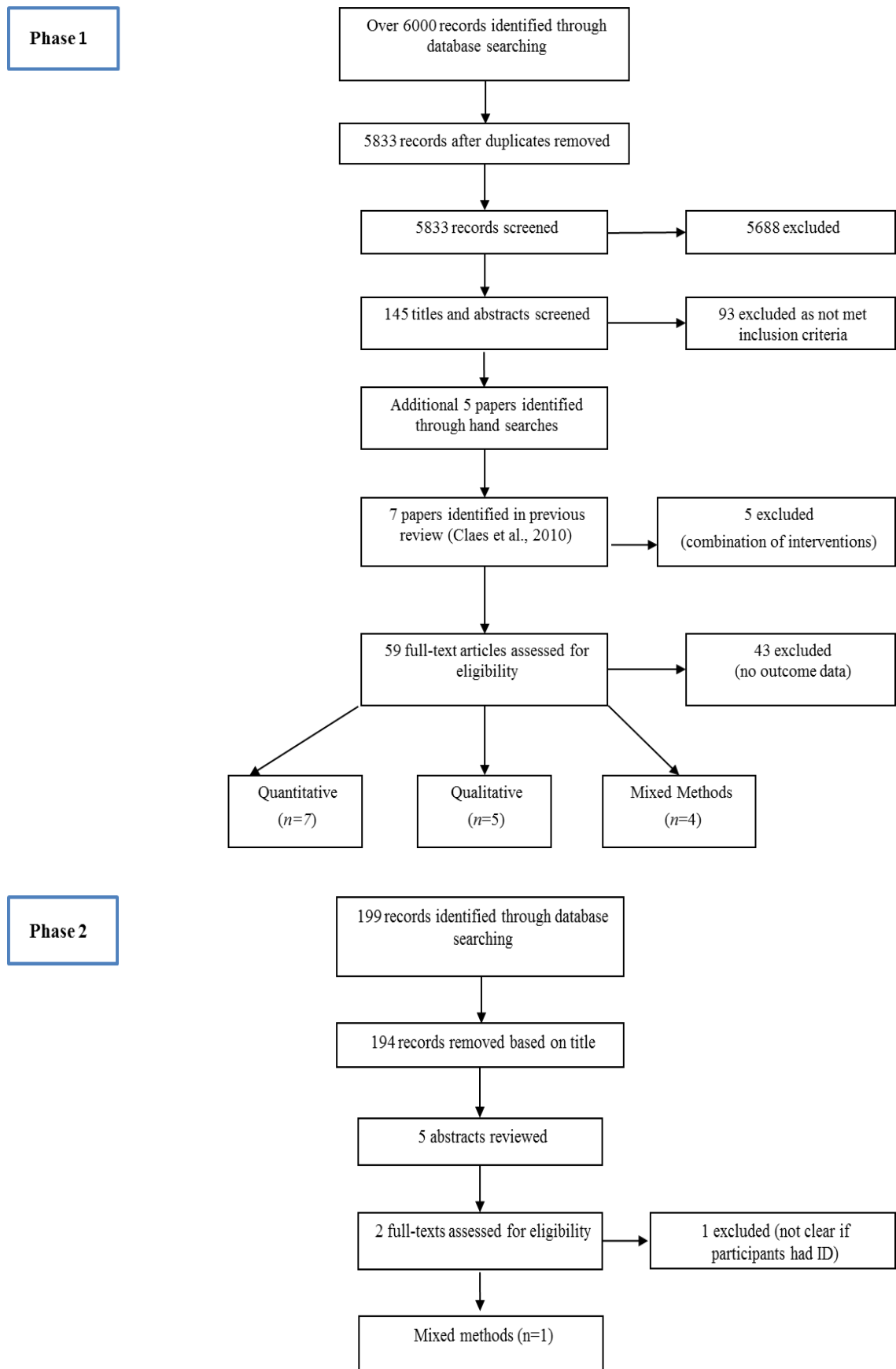
Review Process

Phase 1. The initial searches produced over 6000 potential references which were reduced to a total of 5833 after duplicates were removed. Study selection proceeded as outlined in the flow diagram in Figure 1.1 and after titles of all articles were screened according to the inclusion/exclusion criteria, 145 articles were identified as being potentially relevant for inclusion. Titles and abstracts of these articles were screened and articles that could not be reliably excluded based on the available information were independently assessed by two reviewers against the inclusion/exclusion criteria. A third reviewer was consulted where discrepancies occurred. A further seven studies that were not identified through the electronic searches were considered as they had been included in the review by Claes et al. (2010), however five of these were discarded as they investigated PCP in combination with PBS, whereas the remaining two were considered for full-text review. Hand-searching of references identified five additional papers which were considered for full-text review with a total of 59 texts read in full and assessed for relevance. Sixteen papers were selected for inclusion and 43 studies were excluded as they did not report outcome data.

Phase 2. The results of the updated search covering the period from May 2014 returned a further 199 papers of which 194 were excluded based on title. The titles and abstracts of the remaining papers were screened and two papers were considered for full-text review, although one of them (Corrigan, 2014) was excluded as it was not clear

whether the participants (young people who had experienced school exclusion) had an intellectual disability, therefore one additional paper (Bartle, Crossland, & Hewitt, 2016) was included. A PRISMA flow diagram can be visualised in Figure 1.1.

Figure 1.1 Study selection (PRISMA flowchart)



Analysis and quality assessment.

A structured data extraction form was developed to extract information from each of the included studies (e.g. design, intervention, setting, sample, measures) and for each study the main outcomes of PCP were identified and summarised. A second reviewer assessed the accuracy of the data extraction.

Criteria developed by Downs and Black (1998) were adopted to evaluate the methodological quality of quantitative non-randomised studies (see Appendix A3); they cover reporting, external validity and internal validity. Studies were classified as weak, moderate or strong according to their scores (0-12=Weak; 13-18=Moderate; 18-26=Strong).

Qualitative studies were appraised using criteria adapted from two different papers by Tong, Sainsbury, and Craig (2007) and Mays and Pope (2000) and listed in Appendix A4. Items were scored as 'Y' if they met a criterion and as 'N' if they did not meet a criterion. The total number of 'Y' and 'N' were calculated and each qualitative study was given a score of *strong* if they met 15 or more criteria, *moderate* if they met between 10 and 14 criteria and *weak* if they met between 5 and 9 criteria. Mixed methods studies were appraised according to the most informative aspect of their design. All studies were appraised independently by myself and the second reviewer. Initial inter-rater agreement across all criteria was 86.93% for the quantitative studies and 88.09% for the qualitative studies. The remaining divergences were discussed until consensus was achieved.

Ratings of the impact of PCP on outcomes

A rating scale developed by Prout and Nowak-Drabik (2003) was adopted to provide an indicative score of the impact of PCP on each outcome across the different studies. Scores ranged from 1 (*no effectiveness/no significant change*) to 5 (*marked effectiveness/marked change*), with scores 2-4 representing minimal, moderate and

significant effectiveness respectively. Absolute scores were turned into negatives if the direction of change indicated a negative outcome.

In the quantitative studies outcomes were given a score of 4 or above if there was a statistically significant result for participants receiving PCP. Where there was no statistically significant difference or change, outcomes were given a rating of either 1 or 2; where there was a reported moderate effect or outcomes were approaching statistical significance a rating of 3 was given.

For the qualitative studies scores were given on the basis of what was reported in the text. For example if studies reported “a great improvement” they were given a score of 4, if they reported “no change” they were given a score of 1. Scores do not take into account the quality of each study, so each rating is only reflective of the amount of impact of PCP on each outcome reported in the studies. Scores were given independently by myself and the second reviewer and where discrepancies occurred these were discussed until consensus was reached.

Results

Overview of studies

The current review (including Phases 1 and 2) identified a total of seventeen studies which met the inclusion criteria, seven of which were quantitative in nature, five qualitative and five mixed methods studies. Additionally, four case studies were identified but were not included in the review as they were exclusively descriptive (Certo et al., 1997; Malette, Mirenda, Kandborg, & Jones, 1992; Rea, Martin, & Wright, 2002; Sanderson, 2002). The included studies were published between 1992 and 2016, in the UK, US, New Zealand and Canada and included a total of 700 participants, across the age range (8-84 years old), with various levels of ID (mild to severe). Table 1.2 provides an overview of the included studies grouped by methodology.

Table 1.2. Summary of study characteristics grouped by methodology

Quantitative						
Reference Country	and	Design and Intervention	Participant characteristics	Setting	Measures and Administration	Main Effects
Adams, Beadle-Brown and Mansell (2006). UK.		Between subjects design (N=36): participants grouped on the basis of their Individual Plans' quality (High vs. Low), as all participants had a plan in place.	22 males, 14 females with moderate and mild ID; Age: 20-69, M (SD)=44 (12.81); Adaptive Behaviour Scale scores 69-126, M(SD)=98.5(15.9).	Community-based residential group homes.	Goal Rating Scale (GRS) used to categorise plans. Adaptive Behaviour Scale, and the Lifestyle Satisfaction Scale (LSS), completed by participants or by proxy for less able individuals. Keeping track (staff completed measure of participation in activities). Direct observation (momentary time-sampling every 20s measuring engagement in meaningful activity, contact by participant to staff, contact by staff to participant).	-The only significant difference in outcomes between individuals with high vs low quality plans was in engagement in meaningful activity measured via direct observation, which was higher for those with higher quality plans ($p=0.049$). The Keeping track showed no significant difference in participation in activities. -There was no significant difference ($d= -0.42$) in LSS between people with higher quality plans (N=18, M=53.3, SD=22.6) compared with people with lower quality plans (N=18, M=63.1., SD=23.0). -There was no significant difference between all other variables in the high vs low quality plans groups.
Factor, Sutton, Heller and Sterns, (1996). USA.		PCP Training for participants, staff and family. Quasi-experimental, two groups (N=70, 42 in intervention), pre-post test 6 months follow-up design.	Age: 50 or over (or 35 or over if with Down syndrome), 35-87 years (M=57). ID level: 47% with mild ID and 53% moderate ID	Work sites or day programs with a vocational emphasis.	Inventory for Client and Agency Planning (ICAP; demographic information), Later Life Planning Inventory (LLPI) including the Life Satisfaction Scale, Leisure Inventory, Social Support Network Index, Daily Choice Inventory and Later Life Curriculum Test all completed by participants; Observational Tool.	-Life satisfaction (6-months): significant group-by-time interaction [$F(1,66)=5.64, p=.02$] with scores increasing for those in the control group but decreasing for those in the intervention group. -Participation in recreational leisure activities (6-months): significant increase ($p=0.04$) for those in the intervention group living at home. Overall there was no significant difference between intervention and control group and no main effect for time (Mint ₁ (SD)=.53(.57), Mint ₂ (SD)=.63(.57), Mcon ₁ (SD)=.39(.73), Mcon ₂ (SD)=.67(.54)). -Choice: No significant difference between baseline and follow-up following training (descriptive data) -Participation in meetings (6-months): no significant difference between the two groups ($p>0.10$)

Holburn, Jacobson, Schwartz, Flory and Vietze (2004). USA.	Longitudinal comparative evaluation of intervention (<i>Personal Futures Planning</i> ; N=20) and matched comparison group (traditional <i>Individual Service Planning</i> ; N=18) with approximately 32 months follow-up.	76.9% of the sample were males; Age: 19-61, M (SD)=38.6(9.1); varying degrees of ID and challenging behaviour.	Four developmental centres (state operated congregate intermediate care facilities). All participants were former Willowbrook State School residents with the aim to move to the community.	The Developmental Disabilities Profile 2; Personal Futures Planning Indicators; Indicators of Principles Scale; Person-Centred Planning; Quality of Life Outcome Index. All measures completed by staff.	-Outcome Index (end-point): significantly greater improvement (approximately six times greater) for participants in the intervention group (no figures reported). -A greater proportion of participants in the intervention group moved to community living arrangements at last follow-up (94.7% compared to 27.7%, $p < 0.05$).
Magito-McLaughling, Spinosa and Marsalis (2002). USA.	Quasi-experimental matched-group comparison(N=8), PCP versus control.	Three women and five men (37-41 years old) with moderate to profound ID, autism and/or a secondary psychiatric diagnosis.	Small four-bedroom accommodation with community-based support (experimental group) and traditional residential and day treatment program (comparison group).	Direct observation of participants over one week: community participation/inclusion, choice, respected roles and personal skills.	-Variety of community locations: Alternative model (AM) M=22 per participant compared to M= 5 in the traditional model (TM). -Number of different activities: AM (M=30), TM (M=20). -Variety of activities: Participants in the TM spent more time in "down-time", group trips and passive leisure activities compared to those in the AM who spent more time in active recreation, personal management and community errands. -Inclusive environments: AM participants had more inclusive experiences (86% inclusive, 14% segregated) compared to TM participants (32% inclusive, 68% segregated). -Choice: In the AM 67% of activities participants were engaged in, were preferred compared to 42% in the TM. -Activities in job development or community service per participant per week: AM M=6.3 TM M=4.8 -AM participants displayed less challenging behaviour than their TM counterparts. (Inferential statistics were not reported for any of the data).
Menchetti and Garcia (2003). USA.	One group (N=83) retrospective document analysis of <i>Person-centred Career Plans</i> which had been implemented before the start of the study.	Supported employees; 37 females and 46 males with a mean age of 32 years. Mixed IQ scores ranging from below 59 to 82	Adult agency providing supported employment.	Expressed career choice and employment match (low, moderate, high).	Following PCP 58% were employed in a high preference match job, 29% achieved a moderate preference match, 13% had a low preference match.

Miner and Bates (1997). USA.	Matched group comparison: individuals in each pair randomly assigned to either <i>Person-centred Planning</i> (one PCP meeting prior to transition meeting; N=11) or control (no additional meeting; N=11) with a one month follow-up.	Students with ID enrolled in special education services and their families. Intervention: 7 males, 4 females, IQ 36-71 M= 48.72; Control: 5 males, 6 females, IQ 10-73 M= 47.75	Individualised Education Program/Transition meeting in educational setting	Time-sampling observation of meetings; post-meeting and follow up satisfaction questionnaires completed by family members.	-Parents of those who received a PCP meeting prior to their IEP/transition meeting showed more active participation in meetings compared with parents of those in the control condition. -No significant differences in topics discussed such as “goals selected” or “likelihood of achieving goals”. -Stronger perceptions of change compared with the previous year meeting, for those in the PCP group at follow-up. Parents reported increased children’s participation during meetings compared to previous years.
Robertson, Emerson, Hatton, Elliott, McIntosh, Swift et al. (2006). UK.	PCP Pre-Post-test design with no control group (N=93); follow-up every three months over 2 years.	People with ID from four sites aged 16-86, M(SD)=40.25(12.4), 91% White, with Adaptive Behaviour Scale scores ranging from 10-310, M(SD)=179.9(78.9).	Participants were selected from four different sites which showed a commitment to the implementation of Person-Centred Planning for the enhancement of quality of life. Living arrangements: Group home (62%), Living with informal carer (27%), Locally based hospital unit (7%), Independent Living (3%), Respite (1%).	Adaptive Behaviour Scale, Psychiatric Assessment Schedule for Adults with Developmental Disabilities, Learning Disabilities Casemix Scale, English Indices Deprivation Scale to measure economic level of neighbourhood. <i>Every 3 months:</i> Health Survey for England (scheduled day activities, physical activity); Index of Community Involvement (ICI), Social Network Map, Client Receipt Inventory. <i>Every 6 months:</i> all of the above plus Strengths and Difficulties Questionnaire, Risk Scale, medication info, health problems and level of choice. All measures completed by staff.	-28% of outcomes variables showed significant change from baseline to final data point. -There were significant improvements in size of social network ($p<0.01$), contact with friends ($p<0.01$), number of community activities ($p<0.001$), variety of community activities ($p<0.001$), hours per week scheduled activities ($p<0.05$), and choice ($p<0.01$). -There was an increase in challenging behaviour (hyperactivity; $p<0.05$) and an increase in the reported number of health problems ($p<0.001$). -There was no significant difference of the average service package cost per individual between pre and post PCP implementation.

Qualitative					
Reference and Country	Setting and Intervention	Sample	Data collection and Analysis	Administration	Main Reported Outcomes
Black, McConkey, Roberts, Ferguson (2010). UK.	PCP delivered through the Families Service (supporting and meeting children and carers' needs; two urban and one rural area).	Families (N=48) of children with ID between the ages of 8 and 18 with a range of different support needs.	Thematic content analysis of semi-structured interviews.	Mixed (mainly family carers but also some children with ID and stakeholders)	Improved interpersonal skills, behavioural patterns, communication, social skills and sleep patterns. Increased inclusion and community participation. Reduced aggressive behaviour. 96% of family carers were satisfied with the service for their children.
Espiner and Hartnett (2012). New Zealand.	New facilitation approach of PCP following two days training for staff appointed as facilitators within the organisation (flating/residential group homes).	10 adults (5 males) with ID.	Individual semi-structured interviews analysed through content analysis.	Mixed (adults with ID, family carers and supporters)	Participants reported increased self-determination. Implementation of the plans was not discussed except for one participant who had complained about nothing changing in his life following plan facilitation.
Hagner, Helm and Butterworth (1996). USA.	PCP meeting in transition from school to adult life	16-22 years old (n=6) with different levels of communication ability and varying levels of ID mild (n=2), moderate (n=3) and severe (n=1)	In-depth interviews, participant observation (N=6) and document analysis	Mixed (young adults with ID and family-carers or teachers).	6 months after planning meeting, participants reported that only a few outcomes had been achieved and "not much had happened". However increased sense of closer social connection. More opportunities opened up that seemed unrelated to the meetings but perhaps predisposed individuals to be more open to them such as participation in activities.
Malette (2002). Canada.	<i>Microboards person-centred approach in Homes and community settings</i>	1 male (27) and 2 females (26 and 25) with ID.	Participant observation (community presence, choice, competence, respect and community participation) and semi-structured and unstructured interviews.	Mixed (participants, staff, family and friends)	Reported enhancement of quality of life, choice, empowerment.

Parley (2001). UK.	PCP in Hospital nursing care.	People with ID and nurses	Person-centred service review (PCSR) to monitor service quality (spending time with service-users). Nominal Group Technique (NGT) used to elicit staff views on PCP.	By proxy (nurses)/ observation	Improvements in areas of respect, choice and participation in everyday activities and reported enhancement of quality of life. No improvement reported in involvement of people in planning their care or making major life decision for themselves.
Mixed Methods (qualitative emphasis)					
Reference and Country	Setting and intervention	Participant characteristics	Data collection and Analysis	Administration	Main Reported Outcomes
Kaehne and Bayer (2014). UK.	Application of PCP during transition from school to adult life	Young people with ID in school (N=44)	Retrospective document analysis of nature and content of person-centred plans and telephone interviews.	Retrospective document-analysis; interviews with family members.	Delivering transition meetings in a person-centred manner produced higher rates of stakeholders' attendance compared to those reported in the literature in particular greater involvement for young people and their families. However no outcomes were quantified. Transition planning meetings did not produce improved post-school options.
Truesdale-Kennedy, McConkey, Ferguson, Robertson and Roberts (2006). UK.	Comparison between group receiving service (Families Project, N=27) and contrast groups (N=50) who met inclusion criteria but were located in different areas and therefore were not part of the project; 12 months follow-up	Children with ID ranging from 5-18 years old (M=11), and their families with the majority (72%) of informants being mothers.	Thematic Content Analysis of interviews	by proxy (families)	New Skills (reported by 100% of parents) Increased child's communication (89%), Integration with non-disabled children (84%), increased independence (84%) increased involvement in the community (68%), improved behaviour (47%), improved sleep (26%).

Wigham, Robertson, Emerson et al. (2008). UK.	Four different UK sites followed over 2 years	65 families of people with ID who had received a person-centred plan	Content Analysis of written questions	By proxy (mixed)	Most common reported benefits of PCP reported by direct-care staff were increased activities and opportunities (57%); happier participants (48%), increased empowerment (37%) and choice (37%). More goals were set for participants after the implementation of PCP rather than before.
Mixed Methods (quantitative emphasis)					
Reference and Country	Design	Participant characteristics	Setting	Measures	Main Effects
Bartle, Crossland and Hewitt (2016)	Comparison of before (April 2011- April 2013) and after (April 2013- April 2015) the introduction of a person-centred planning meeting (Planning Live) facilitated by the Enhanced Support Service for patients referred for possible inpatient admission.	102 adults (53 males) with ID and additional needs which warranted referral to inpatient unit ; Age 18-75) M = 39. 84% White British.	PCP meetings were held at the local psychiatric hospital after a referral had been made or following emergency inpatient admissions.	-Admission to inpatient services -Length of inpatient admissions	-There was an increase in inpatient admissions from before the introduction of Planning Live (30) to after its introduction (42), although data on number of referrals prior to intervention is missing. -There was a significant reduction (Mann Whitney $U = 457$, $Z=1.97$, $p<0.05$) in the length of admissions following the introduction of PCP meetings. -Respondents gave an average score of 4.46 on a scale from 1 to 5 when they asked if they found the process to be helpful
Heller, Miller, Hsieh and Sterns (2000). USA.	PCP training for individuals with ID, staff and family members. Quasi-experimental, two groups (N= 60, 38 in intervention), pre-post-test design with 6 months follow-up (questionnaires) and 10 months follow-up (goals attained, intervention only).	People with ID aged 50 or over (or 35 or over if with Down syndrome) age range: 35-84, M(SD)=56.92(10.83). Level of ID: mild (52%), moderate (48%).	Day programs with a vocational emphasis.	Inventory for Client and Agency Planning (ICAP; demographic information), Later Life Curriculum Test, Life Satisfaction Scale, Daily Choice Inventory, Goal Attainment completed by participants and direct observation.	-There was a greater increase in choice-making from pre to post intervention for participants in the intervention arm compared to the control group $F(1-58)=7.58$, $p<.01$, however this was only for two items, "How to decorate your room" and "What job/work you do at the workplace". -No significant differences between groups and no significant main effect over time on life satisfaction -3.4% of participants in the intervention arm who set goals exceeded expectations of goal attainment, 55.2% met expectations, 28.7% partially met expectations and 12.6% did not meet expectations.

Variations in PCP evaluation

Twelve studies prospectively evaluated the effectiveness of PCP, two studies evaluated the impact of a PCP training program for individuals with ID, staff and family members (Factor, Sutton, Heller, & Sterns, 1996; Heller, Miller, Hsieh, & Sterns, 2000); two studies evaluated the effect of PCP retrospectively by conducting document analyses (Kaehne & Beyer, 2014; Menchetti & Garcia, 2003) and one study compared outcomes in people with ID based on the quality of their person-centred plans (Adams, Beadle-Brown, & Mansell, 2006).

Quality of studies

Table 1.3 and 1.4 show the scores for the quality appraisal for quantitative and qualitative studies respectively. Higher scores indicate higher quality.

Quantitative studies

Table 1.3. Quality assessment of quantitative studies

Reference	Reporting/10	External Validity/3	Internal Validity/14	Total/26
Adams et al. (2006)	8	0	6	14
Bartle et al. (2016)*	7	0	6	13
Factor et al. (1996)	8	1	7	16
Heller et al. (2000)*	8	1	8	17
Holburn et al. (2004)	7	1	7	15
Magito-MacLaughling et al. (2002)	5	0	5	10
Menchetti and Garcia (2003)	5	3	5	13
Miner and Bates (1997)	5	1	7	13
Robertson et al. (2006)	5	1	6	12

*Although the studies were presented as mixed methods studies, the qualitative aspect of the study were minor and not related to outcomes for people with ID, therefore they were evaluated as quantitative studies.

The majority of the studies were of moderate quality and none were rated as strong quality. There were no randomised controlled trials (RCTs). Six quantitative studies included a comparison group (Adams et al., 2006; Factor et al., 1996; Heller et al., 2000; Holburn et al., 2004; Magito-McLaughlin, Spinoso, & Marsalis, 2002; Miner & Bates, 1997) but only in one of them participants were randomly assigned to PCP (Miner & Bates, 1997); allocation was not concealed. Other potential sources of bias common across the studies were:

- Unrepresentative samples and poor external validity (all except Menchetti and Garcia (2003));
- No blinding of outcome assessment (all except Magito-McLaughlin et al. (2002));
- Lack of clear descriptions of PCP components (all except Holburn et al. (2004));
- Inadequate fidelity assessment (all studies; brief mention of implementation fidelity was reported in Robertson et al. (2006)).
- Incomplete reporting of findings (all except Adams et al. (2006) and Heller et al. (2000))

Qualitative studies

Table 1.4. Quality assessment of qualitative studies

Reference	Total Yes	Total No	Overall quality
Black et al. (2010)	10	11	Moderate
Espiner and Hartnett (2012)	12	9	Moderate
Hagner et al. (1996)	14	7	Moderate
Kaehne and Bayer (2014)*	7	14	Weak
Malette (2002)	11	10	Moderate
Parley (2001)	5	16	Weak
Truesdale-Kennedy et al. (2006)*	7	14	Weak
Wigham et al. (2008)*	8	13	Weak

*Although these studies used mixed methods the qualitative aspects were prominent and therefore they were evaluated as such.

The quality of the qualitative studies was moderate at most and common study flaws were:

- Lack of clear descriptions of how the data were recorded (e.g. audio-taped) (all except Espiner and Hartnett (2012), Hagner, Helm, and Butterworth (1996) and Malette (2002));
- A lack of explicit descriptions of the coding process, its reliability and of how the themes were analysed (all except Hagner et al. (1996) and Wigham et al. (2008));
- Lack of discussions regarding reflexivity (all except Espiner and Hartnett (2012) and Malette (2002)) and data saturation (all studies);
- No feedback from participants on the findings to determine validity of their interpretation (except in Malette (2002) and Parley (2001)).

Outcomes

Outcome ratings

The most commonly investigated outcomes in the reviewed studies were daily choice-making, participation in activities and social networks/relationships. The former two outcomes were among those which appeared to be most positively influenced by PCP, along with community participation and quality of life. PCP did not appear to be effective in improving outcomes related to health, behaviour, adaptive functioning and self-reported life satisfaction. Although PCP led to shorter inpatient admissions, it also led to an increase in the number of admissions in one study (Bartle et al., 2016). Details of the outcomes, measures and ratings of impact of PCP on outcomes are presented in Table 1.5.

Table 1.5. Outcome ratings

Outcome variable/reference	Measure	Score (1-5)	Mean score
<i>Quality of life</i>			3.6
Parley (2001)	PCSR/NGT	3	
Malette (2002)	Participant Observation/Interviews	3	
Holburn et al. (2004)	Quality of Life Outcome Index	5	
<i>Life satisfaction</i>			0
Adams et al. (2006)	Life Satisfaction Scale	-1	
Factor et al. (1996)	Life Satisfaction Scale*	-4	
Heller et al. (2000)	Life Satisfaction Scale*	1	
Wigham et al. (2008)	Content Analysis	4	
<i>Choice-making</i>			3.4
Factor et al. (1996)	Daily Choice Inventory	1	
Heller et al. (2000)	Daily Choice Inventory	4	
Magito-McLaughling et al. (2002)	Direct Observation	4	
Malette (2002)	Participant observation/ interviews	4	
Parley (2001)	PCSR/NGT	4	
Robertson et al. (2006)	No specified measure	4	
Wigham et al. (2008)	Content Analysis	3	
<i>Self-determination</i>			2.5
Espiner and Hartnett (2012)	Content Analysis	3	
Hagner et al. (1996)	Interviews, participant observation, document analysis	2	
Factor et al. (1996)	Observation of Individual Service Plan Meeting (Individuals' participation)	2	
Malette (2002)	Participant observation/ interviews	4	
Parley (2001)	PCSR/NGT	1	
Wigham et al. (2008)	Content Analysis	3	
<i>Participation in Activities</i>			3.4
Adams et al. (2006)	Keeping Track; Direct Observation	3	
Robertson et al. (2006)	Index of Community involvement	4	
Hagner et al. (1996)	Interviews, participant observation, document analysis	3	
Factor et al. (1996)	Leisure Inventory	2	
Magito-McLaughling et al. (2002)	Direct Observation	3	
Parley (2001)	PCSR/NGT	4	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	4	
Wigham et al. (2008)	Content Analysis	4	
<i>Community Participation</i>			4.5
Magito-McLaughling et al. (2002)	Direct Observation	5	
Malette (2002)	Participant observation/ interviews	4	
Robertson et al. (2006)	Index of Community involvement	5	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	4	
<i>Social Networks/Relationships</i>			3
Black et al. (2008)	Thematic Content Analysis	4	
Espiner and Hartnett (2012)	Content Analysis	2	
Hagner et al. (1996)	Interviews, participant observation, document analysis	3	
Magito-McLaughling et al. (2002)	Direct Observation	2	
Parley (2001)	PCSR/NGT	1	
Robertson et al. (2006)	Social Network Map	4	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	5	
<i>Behaviour</i>			1.75
Black et al. (2008)	Thematic Content Analysis	3	
Magito-McLaughling et al. (2002)	Direct Observation	4	
Robertson et al. (2006)	Strengths and Difficulties questionnaire	-3	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	3	
<i>Adaptive Functioning</i>			1
Adams et al. (2006)	Adaptive Behaviour Scale	1	
<i>Employment</i>			2
Robertson et al. (2006)	Demographics	1	
Menchetti and Garcia (2003)	Document Analysis of expressed job preference and obtained employment match	4	
Magito-McLaughling et al. (2002)	Direct Observation	3	
Kaehne and Beyer (2014)	Content Analysis	1	

Outcome variable/reference	Measure	Score (1-5)	Mean score
Heller et al. (2000)	Expressed Goals	2	
Malette (2002)	Participant observation/ interviews	1	
<i>Health</i>			-1.5
Robertson et al. (2006)	Health Survey for England	-4	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	1	
<i>Moves and admissions</i>			2.3
Holburn (2004)	%of people who have moved to community	5	
Bartle et al (2015)	Length of inpatient admission	5	
	Number of admissions	-3	

PCSR= Person-Centred Service Review

NGT = Nominal Group Technique

*Adapted from the Life Satisfaction Scale for Aging Adults with Mental retardation

Primary Outcomes

Quality of life.

Qualitative studies described quality of life enhancements for individuals following the implementation of PCP (Malette, 2002; Parley, 2001). Participants reported looking at their lives differently, feeling better, more confident and happier as a result of PCP (Wigham et al., 2008).

Only one study evaluated quality of life in a comparison study (matched groups) and found that participants receiving PCP had a six times greater improvement in scores in a composite quality of life measure compared with those in the control condition within a traditional Individual Service Planning framework (Holburn et al., 2004). In the study, the PCP Quality of Life Indicators Scale, was incorporated with items from other scales to form The Outcome Index, a composite measure which also includes items on autonomy and choice, activities, health, relationships, community places, respect, competence and satisfaction. Scores were calculated for the scale as a whole and there are no reported data for each subscale so it is unclear from the paper whether improvements occurred for each subscale or for just a few.

Life Satisfaction

Three studies measured self-reported life-satisfaction and found no significant positive effect of PCP (Adams et al., 2006; Factor et al., 1996; Heller et al., 2000). Factor et al.

(1996) found that following PCP training for older adults with ID, their family members and staff, six-months follow-up scores on the life satisfaction scale increased for those in the control condition (n=38) but counter-intuitively decreased for those who had received PCP training (n=42). In a subsequent study with a similar methodology no significant difference was found between life satisfaction scores for participants who received PCP training (n=38) and a comparison group (n=22); there was also no significant main effect for time (Heller et al., 2000). Table 1.6 represents life satisfaction scores for participants in both studies. Adams et al. (2006) also found no significant difference in life satisfaction between people with higher quality plans compared with people with lower quality plans.

Table 1.6. Life Satisfaction Intervention vs. Comparison group

Study	Control			Intervention		
	Baseline Mean (SD)	Follow-up Mean (SD)	Mean Change	Baseline Mean (SD)	Follow-up Mean (SD)	Mean Change
Factor et al., (1996)	0.45 (0.47)	0.59 (0.37)	0.14	0.62 (0.40)	0.57 (0.40)	-0.05
Heller et al., (2000)	0.71 (0.28)	0.70 (0.30)	-0.01	0.61 (0.33)	0.64 (0.53)	0.3

Daily Choice-Making.

Seven studies explored the impact of PCP on choice-making and all but one found that the approach had a positive impact on this outcome.

Two qualitative studies are indicative of a positive effect of PCP on everyday choice-making (Malette, 2002; Parley, 2001) and Wigham et al. (2008) reported that 37% of their sample mentioned improved choice-making as one of the main benefits of a PCP intervention.

Four quantitative studies evaluated the impact of PCP on choice-making and three of them found a positive effect. Robertson et al. (2006) found that after the implementation of PCP, participants with ID were 2.8 times more likely to participate in choice-making compared to baseline. Magito-McLaughlin et al. (2002) found that four participants living in settings where PCP was applied were more likely to engage in

preferred activities compared to four participants living in a traditional model, suggesting that those in the PCP group were able to exercise more choice. Heller et al. (2000) found that compared to a control group, older adults with ID who received PCP training had a greater increase in choice-making from pre to post-intervention. Only one study evaluating the impact of PCP training on daily choice-making found no significant impact on such outcome (Factor et al., 1996).

Self-determination.

The impact on self-determination, which has been defined as “acting as the primary causal agent in one’s life and making choices and decisions regarding one’s quality of life free from undue external influence or interference” (Wehmeyer, 2005, p.117), was explored in six studies. Three studies suggest a positive effect of PCP on self-determination and empowerment: 37% of participants in Wigham et al. (2008) reported that following PCP they experienced a greater feeling of empowerment and control over their situation which was also observed in individuals in a qualitative study by Malette (2002); similarly adults with ID in a qualitative study by Espiner and Hartnett (2012) reported that they had developed an increased sense of self-determination following their PCP meeting.

Another three studies however suggest that PCP may only have a limited impact on self-determination. In a qualitative study of PCP with six individuals, Hagner et al. (1996) reported that although individuals actively participated in choosing the location, time and attendees of the meeting, they were often overpowered by staff or family members, and at times their contributions were ignored or reinterpreted, as not conforming to the agenda of the planning process. Parley (2001) argued that following PCP in a nursing hospital setting there was no significant improvement in involving patients in planning their own care and no major life decisions were made by individuals during the course of the study. In Factor et al. (1996) no significant difference in individuals’ active participation in their meetings was found between a

group who received PCP training and those who did not; this is despite the fact that those who received PCP training received more encouragement from staff to contribute to their meeting than those in the control group.

Participation in activities.

Eight studies described the impact of PCP on participation in activities suggesting that the approach has a moderate positive impact on this outcome.

Four studies quantitatively evaluated the impact of PCP on participation in activities and produced mixed findings, in that only two of the studies which prospectively evaluated the impact of PCP on participation in activities found a positive impact on the outcome (Magito-McLaughlin et al., 2002; Robertson et al., 2006). Factor et al. (1996) found that PCP training for older adults with ID had a positive impact only for those living in the family home. Adams et al. (2006) compared individuals with high and low quality plans in participation in activities. Whereas a staff-completed measure showed no significant difference between groups, direct-observations from researchers showed that participants with higher quality plans spent significantly more time engaged in meaningful activities than those with lower quality plans. Findings from two qualitative studies (Hagner et al., 1996; Parley, 2001) and two mixed-methods studies (Truesdale-Kennedy, McConkey, Ferguson, & Robertson, 2006; Wigham et al., 2008) indicated that PCP has a positive impact on participation in activities.

Community Participation.

Four studies found that PCP had a positive effect on community participation. In a qualitative study Malette (2002) reported that participants within a PCP framework had the opportunity to experience greater involvement in the community. This was also reported by 68% of participants in a mixed-methods study (Truesdale-Kennedy et al., 2006) and documented in two additional quantitative studies (Magito-McLaughlin et al., 2002; Robertson et al., 2006).

Social Networks/Relationships.

Evidence from seven studies on the impact of PCP in improving relationships and expanding social networks for people with ID is inconsistent. Robertson et al. (2006) reported a statistically significant 52% increase in social networks size following the implementation of PCP, however this did not extend to include people other than close family or staff. In another quantitative study Magito-McLaughling et al. (2002) found no significant difference in the average amount of social contact between participants in a traditional model compared with those in a person-centred model. Whereas 11 social contacts (total of 9.1 hours per week) were recorded for participants in the traditional model, 14 social contacts were recorded for those in the PCP model (total of 9.2 hours/per week). There was however an important difference as in the traditional model only one out of four participants had all the recorded social contact whereas in the person-centred model three out of four had some form of external social contact.

In the studies where PCP was implemented with families it was reported that one of the most favourable aspects of PCP was that children had increased opportunities to mix with non-disabled peers and participate in more inclusive social relationships (Black, McConkey, Roberts, & Ferguson, 2010; Truesdale-Kennedy et al., 2006). Evidence from three qualitative studies however indicated that PCP did not appear to have a significant impact on people's social networks. Hagner et al. (1996) argued that although the planning process seemed to play a role in bringing people closer together and enhancing social relationships between individuals and their relatives and friends, most individuals continued to have very few friendships with peers. Parley (2001) reported that participants' family involvement remained unaffected by PCP and Espiner and Hartnett (2012) highlighted that only few family members and no other community members that could enable community connections attended PCP meetings, therefore reducing opportunities for further interactions.

Secondary Outcomes

Behaviour

The impact of PCP on behaviour was reported in four studies. Three studies reported improvements in behavioural patterns (Black et al., 2010; Magito-McLaughlin et al., 2002; Truesdale-Kennedy et al., 2006) with challenging behaviours occurring less frequently and in fewer contexts in a person-centred paradigm (Magito-McLaughlin et al., 2002). Only Robertson et al. (2006) assessed the statistical significance of the impact of PCP on behaviour and counter-intuitively found that there was a significant increase in hyperactivity (37%) following PCP implementation as well as a non-significant increase in emotional problems (59%) and decrease in prosocial behaviour (14%).

Adaptive Functioning.

The only study which reported differences in adaptive functioning (measured with the Adaptive Behaviour Scale Part 1; Nihira, Leland and Lambert, 1993) found no differences in scores between participants with high and low quality plans (Adams et al., 2006).

Employment.

Six studies described employment outcomes and produced inconsistent evidence. A positive effect of PCP on future employment was found in a retrospective study of person-centred career planning and subsequent employment matches (Menchetti & Garcia, 2003). The study found that out of 83 individuals with ID who received person-centred career planning, more than half obtained employment which matched their preferred occupation and location which they had expressed in their vision statement.

Mixed findings were reported by Magito-McLaughling et al. (2002) who compared four people in a PCP model with four people in a traditional model. They found that people in the traditional model were more involved in both volunteer and paid work and stayed

in the same role for long periods of time. On the other hand those in the PCP model were more involved in activities such as job development or community service and were given the opportunity to sample more jobs in order to identify preferences.

In other studies PCP did not have any significant impact on employment outcomes (Malette, 2002; Robertson et al. 2006) and Kaehne and Beyer (2014) expressed concern that at post-school transition planning meetings there was a lack of external employment agencies. The authors argued that this would limit post-school options and work outcomes for young people with ID. Heller et al. (2000) reported that there were significant barriers to implementing employment related goals such as changing jobs or workplace due to the limited availability of work places and opportunities.

Health

Two studies described health outcomes of PCP. In Truesdale-Kennedy et al. (2006) health improvement was set as a PCP goal for 37% of participants, however for 54% of these this goal was unmet post-PCP and only 6% reported health improvement as one of the main benefits of PCP. Robertson et al., (2006) was the only study that assessed the statistical significance of health outcomes from baseline to final time-point and found there was a statistically significant 67% increase in reported health problems.

Moves and admissions

One study found that a greater proportion (94.7%) of people who had received a person-centred plan moved from institutional living to community settings within the timeframe of the study, compared to their counterparts in a traditional service (27.7%) (Holburn et al., 2004). In contrast however another study found that following the introduction of a PCP meeting in an enhanced support service for people with ID considered for inpatient admission, the number of admissions actually increased from 30 in the pre-PCP period to 42 in the post-PCP period. The length of stay of each admission however decreased significantly (Bartle et al., 2016).

Discussion

Summary of findings

The present review endeavoured to provide a broad overview of the status of research on PCP for people with ID and to evaluate its effectiveness in terms of outcomes most likely to be influenced by PCP. Seventeen studies were included in the review. It is concluded that PCP may have a moderate positive impact on a variety of outcomes and has the potential to ameliorate and enrich aspects of quality of life for people with ID. PCP was shown to have a significant positive impact on community participation, and a moderate positive impact on quality of life, participation in activities and everyday choice-making. Although everyday choice-making generally improved, participants' self-determination did not improve accordingly. Despite participants being more involved in everyday choices, in the research there is no significant evidence of people gaining greater control in shaping their lives, driving decision-making and planning their care. From the review, there is no evidence that PCP is effective in improving problem behaviour and adaptive functioning. Generally, the evidence for the benefits of PCP is not conclusive, as for all outcomes with the exception of community-participation, there were discrepancies between findings from different studies in that not all the studies reviewed consistently found positive outcomes for the variables considered.

Counter-intuitively Robertson et al. (2006) found that PCP had a negative impact on reported health problems for people with ID, however as argued by the authors, it is likely that PCP helped care-givers become more aware of health problems and health needs rather than making people unhealthy. In a similar fashion the decrease in life satisfaction scores following PCP training in Factor et al. (1996) might have been due to participants gaining awareness of their potential options and noticing the limitations of their circumstances. It could therefore be argued that rather than PCP having a direct negative impact on outcomes, it is more likely that the approach can help to uncover shortcomings in individuals' lives and shed light on potential negative aspects.

Interestingly in one study the number of admissions increased following the introduction of a PCP meeting in the service. The authors however argued that this may have been due to an increase in the number of referrals to inpatient admissions following the implementation of PCP, driven by the fact that patients wanted to access the intervention, and the only way to access it was via referral (Bartle et al., 2016).

The review was unable to show any associations between PCP effectiveness and age, level of ID or PCP approach used. The review included research that explored the effectiveness of PCP in a variety of settings, however due to the small number of studies it was not possible to determine if certain contexts lend themselves to a more successful implementation of PCP. The present review cannot be classified as providing a conclusive level of certainty of the effectiveness of PCP.

Limitations of the included literature

The literature appraised here presents several limitations and therefore findings should be interpreted with caution. There is substantial heterogeneity in the body of evidence due to the mixture of methodologies and designs, the variety of contexts and the different population groups under study. Nearly half the included studies investigated PCP in times when participants were experiencing significant transitions (e.g. leaving school, moving to employment, adjusting to later-life) and this may have differential effects from PCP when applied in an established setting where a pre-existing system is already in place. Outcome measures also differed across studies, thus it was not possible to combine findings across studies. The ratings in Table 1.5 constituted an attempt to summarise the impact of PCP for each outcome, however weights were not assigned to each study based on methodological rigor so the scores do not account for methodological bias.

As a whole the literature is subject to significant bias: there were no RCTs investigating the effectiveness of PCP and studies were of moderate quality at most. Only half the

studies included a control group and a quarter of the studies had small sample sizes (N=10 or less).

Selection bias is a common issue in the studies reviewed with the great majority including context-specific samples (e.g. young people in educational settings) not representative of the ID population as a whole. Furthermore, in many of the studies it is not clear how participants were selected and only three studies (Hagner et al., 1996; Kaehne & Beyer, 2014; Truesdale-Kennedy et al., 2006) stated how many potential participants were approached to take part. Studies also presented a risk for response bias as only three studies gathered responses directly from individuals with ID. In these studies however, participants either received training in PCP (Factor et al., 1996; Heller et al., 2000), or were compared based on the quality of their plans (Adams et al., 2006) and no actual PCP intervention was implemented. Responses offered by staff and family members in other studies may not have been truly reflective of the individuals' experience and possibly influenced by social desirability.

Adherence to PCP was poorly documented with only one study monitoring implementation fidelity (Robertson et al., 2006). In the majority of the studies the PCP interventions and their components were not clearly described, making it difficult to determine which aspects or combination thereof are better suited for achieving specific results. The lack of clear descriptions of the interventions also poses a challenge to future replications and confirmation of findings.

Challenges of PCP implementation

Despite the limitations of the literature some tentative inferences can be drawn from the studies. PCP is unlikely to be a *panacea* for all aspects of the lives of people with ID and more significant changes will be found in areas specifically tackled by the PCP process. Menchetti and Garcia (2003) for example found that PCP had a positive significant impact on employment outcomes for people with ID. The study however was conducted in supported employment agencies and the purpose of PCP was to

determine career choices for supported employees. In studies where employment was not a specific outcome of PCP, changes in this outcome were minimal, reflecting that outcomes can vary considerably depending on the context in which PCP is adopted.

It can be argued that the effectiveness of PCP is dependent upon the number of outcomes to be pursued, effort, resources and time required. When many outcomes are considered it is unlikely that the same level of success is achieved across all. Robertson et al. (2006) found that only 28% of all dependent variables measuring aspects of quality of life changed significantly following the implementation of PCP. It is arguable that the variables where no significant change was observed may have not been personally meaningful to the individuals in the study. One of the challenges of the evaluation of PCP is identifying personally-attuned outcomes for participants, which can only be achieved when individuals are directly involved in decision-making. Active participation in decision-making is also likely to result in better outcomes and fewer unmet needs (Puschner et al., 2015).

Data from Menchetti and Garcia (2003) highlight that PCP has the potential to fade after initial meetings and indeed in their study they found that following an initial PCP meeting, 47% of the reviewed plans had not received an annual update. Furthermore only 5% received two annual updates, thus suggesting that there might be over-emphasis on the first PCP meeting, the results of which may be at risk of subsiding if not continuously revitalised. This issue has been described as one the possible causes of PCP failure (Holburn & Cea, 2007) and it is common across psychosocial interventions which are often subject to issues of fading after initial improvements (Unwin, Tsimopoulou, Kroese, & Azmi, 2016). Robertson et al. (2006) argued that PCP may have more positive impact on outcomes which have short-term relevance such as choice-making and participation in activities. Significant impact on longer-term goals such as employment or more inclusive social networks (other than family and friends) may be more difficult to achieve, and from the available literature it can be argued that the effectiveness of PCP on such outcomes is limited. Robertson et al. (2006)

demonstrated that sustained delivery of PCP may be difficult given the diverse service models and local configurations. Even within the context of a well-resourced research project where expert input was available, for nearly a third of participants (30%) a plan was not developed within the timeframe of the study, suggesting that widespread adoption of PCP could face significant challenges in contexts where resources are more limited and expert advice may not be readily accessible. Another issue that is important to consider with regards to the failure to implement PCP is that, as demonstrated in previous research, it is difficult to implement new approaches within existing services which usually have an established culture within their organisation which is often resistant to change (Beckett et al., 2013). Furthermore, longer follow-up periods than those reported in the studies in this review (longest follow-up was 32 months) may be required to observe a significant impact of PCP.

Previous studies have elucidated how difficult it is to empirically evaluate the quality of individual plans and to monitor their implementation (Adams et al., 2006). Research by Poppes, Van der Putten, and Vlaskamp (2014) also revealed that individualised plans often lack important information. Indeed they found that for a sample of people with multiple and profound ID who also displayed challenging behaviour, only 51.8% of their challenging behaviours were described in the individualised plans; furthermore for only 53.7% of these challenging behaviours, recommendations on strategies to deal with the behaviour were presented in the plan, and only 17.2 % of the plans contained guidelines for prevention or reduction of the challenging behaviour. These figures are in accordance with data provided by Stancliffe, Hayden, and Lakin (1999) who found that only 54% of a sample of people with challenging behaviour (n=151) had an Individual Habilitation plan objective for challenging behaviour.

Moving beyond the generation of a plan requires continuous effort from individuals, family members and staff to work towards desired goals. Unfortunately, initial meetings are not always followed by significant actions; Wigham et al. (2008) found that even though many more goals were set for participants after the implementation of PCP, at a

2-year follow-up there was still a high proportion of goals that had not been met. Poppes et al. (2014) suggested that in practice individualised plans may not actually be used by staff to guide support.

The failure to carry plans through into practice (implementation gap) has been the cause for strong criticism of PCP as a mere paper exercise which often has no real impact on service-users' lives (Mansell & Beadle-Brown, 2004c). It is of crucial importance that person-centred planning leads to person-centred action in order to bring significant change and this is what services should be placing emphasis on, as action is what is crucial to achieve the right support, even without a formalised planning system (Mansell & Beadle-Brown, 2004b). Greater importance should therefore be placed on the quality of care provided and extent of person-centred support rather than the presence of a written support plan: "For people being supported by services it is not person-centred planning that matters as much as the pervasive presence of person-centred thinking" (Sanderson & Smull, 2011, p.1). The failure to carry out action on individual plans may constitute an explanation as to why no consistent relationship has been found between good quality person-centred plans and quality of life outcomes in people with intellectual disabilities (Mansell & Beadle-Brown, 2004c).

Conclusion

Empirical support for the effectiveness of PCP is still fragmented even though attempts have been made to quantitatively measure its impact. Despite the policy argument for the adoption of PCP, there is uncertainty regarding its long-term outcomes and the ways in which challenges to the implementation of PCP may be overcome.

Existing successful small scale demonstrations of the effectiveness of PCP in improving the quality of life of people with ID provide cautious optimism for this approach. Some have argued that PCP can now be considered as an evidence based practice (Sanderson, Thompson, & Kilbane, 2006), however, as suggested by Hagner et al. (1996), the challenge of the application of PCP on a wider scale remains. The

question is therefore not whether PCP should be implemented, but how its effectiveness can be sustained in ordinary practice.

Since the publication of *Valuing People Now* (DOH, 2009) only three new studies have been conducted in the UK (Bartle et al., 2016; Black et al., 2010; Kaehne & Beyer, 2014) and one was conducted in New Zealand (Espiner & Hartnett, 2012), suggesting that evidence lags behind policy recommendations. To date, as concluded in this review, there is still no sufficient evidence to support the notion that PCP can achieve sustained and substantial change in the lives of people with ID as originally anticipated (Department of Health, 2001).

Finally, it has been suggested that devising individualised support plans is not always common practice, particularly for those with more severe ID, communication difficulties, challenging behaviour and mental health disorders, who not only are less likely to receive a plan, but are also most often not involved in the planning process (Claes et al., 2010)

It has been argued that the presence of an individualised support plan is worthless if it is not implemented and facilitated by carers. If plans are not used as real working documents to guide practice they are not sufficient to make a difference in people's life (Mansell & Beadle-Brown, 2004a, 2004b). A person-centred plan should not be the outcome of PCP; it should instead be the first step towards the delivery of person-centred support.

Section 1C: The present project

This chapter provided an introduction to ID and provided a brief overview of the care trends for this population in the recent past.

Despite the fact PCP has been widely acclaimed and that in the 2001 White Paper *Valuing People* it was envisaged as the primary vehicle for change in the delivery of care for people with ID, the systematic review demonstrated that the evidence for the effectiveness of PCP is still limited and fragmented. Plans are meaningless if they are not followed by concrete action, and conversely, significant outcomes can be achieved without the presence of formalised plans. What truly matters is moving from plan to practice and providing person-centred support in everyday life.

The review also showed that the effect of PCP on behaviour was inconsistent, with a study by Robertson et al (2006) counter-intuitively finding increases in challenging behaviour following the introduction of PCP.

Given the lack of clear and consistent outcomes of previous research, the aim of the present thesis is to explore everyday person-centred support in adults with ID and challenging behaviour living in the community and supported by paid carers.

This thesis aims to answer the following questions:

- Is the support received by people with ID and challenging behaviour in their day-to-day lives person-centred?
- Are there any correlates of person-centred support? If so what are they?
- Is person-centred support inversely associated with challenging behaviour?
- What is the evidence from direct-observation perspectives of person-centred support?

The project is set within the context of a multi-centre randomised controlled trial funded by the National Institute of Health Research HTA Program (project number 10/104/13) investigating the clinical and cost-effectiveness of training health professional in

Positive Behaviour Support (PBS) techniques for the reduction of challenging behaviour in people with ID (Hassiotis et al., 2014). All the participants described in the studies in this thesis have been described as having challenging behaviour.

Chapter 2. Challenging behaviour, Person-centred support and choice: an overview

Introduction

At the end of the previous chapter I explained that the aim of the thesis is to explore everyday person-centred support in adults with intellectual disabilities and challenging behaviour living in the community and supported by paid carers.

Given the focus of the research, in this chapter I provide an overview of the key constructs in the present thesis, namely challenging behaviour, person-centred support and choice.

Challenging behaviour

Challenging behaviour has been defined as "culturally abnormal behaviour(s) of such intensity, frequency or duration that the physical safety of the person or others is placed in serious jeopardy, or behaviour which is likely to seriously limit or deny access to the use of ordinary community facilities" (Emerson & Einfeld, 2011, p.4). The term is typically used to describe behaviour of people with ID which poses a challenge to services, such as aggressive or other socially inappropriate behaviour; it is thought that between 10-15% of people with ID exhibit such behaviour (Emerson et al., 2001).

Challenging behaviour has been repeatedly associated with risk of serious harm to the individual's physical and psychological well-being, and leads to higher levels of hospitalisation, medication intake, and other negative effects such as increased risk of abuse, social exclusion, systematic neglect, placement breakdown and high staff turnover (Heyvaert, Maes, Van den Noortgate, Kuppens, & Onghena, 2012; MacDonald & McGill, 2013). Challenging behaviour is also considered to be

detrimental for the development of social relationships and participation in community activities.

Three major forms of challenging behaviour have been identified which are aggressive/destructive behaviour, self-injurious behaviour and stereotypy. Aggressive/destructive behaviour is typically directed outwards and involves actions such as biting, scratching, hitting or throwing objects at others. In self-injurious behaviour physical violence or aggression is directed to the self and common actions are picking, biting, head banging etc. Stereotyped behaviour includes repetitive behaviours such as body rocking or echolalia (Emerson & Einfeld, 2011).

There are various factors which have been suggested to be potential risk markers for the development of challenging behaviour and these include gender, with males being more likely than females to present challenging behaviour, age, with challenging behaviour being more prevalent in younger adults compared to older individuals, degree of intellectual impairment, with challenging behaviour being more common amongst persons with a severe learning disability, degree of sensory and communicative impairment and having a diagnosis of autism (Holden & Gitlesen, 2006; McClintock, Hall, & Oliver, 2003). Sappok et al. (2014) suggested that the predominant causes of increased risk factor for challenging behaviour are the presence of autism spectrum disorder (ASD) and the severity of intellectual disability.

Despite the fact that there are known personal characteristics that predispose individuals to have greater risk of presenting with challenging behaviour, it has often been argued that some of the behaviours exhibited by people with ID which are considered to be challenging are not solely attributable to internal and personal characteristics, but are in fact just as attributable to an unsupportive social environment in which the individual's needs are unmet (Willems, Embregts, Stams, & Moonen, 2010). It is generally agreed that challenging behaviour is not an absolute pathological condition, or caused by 'problems' within the individual, but it is in fact the artefact of

the interaction between the individual and his/her surroundings which include the material environment, the opportunities it presents and the network of people around him/her (Lowe, Felce, Perry, Baxter, & Jones, 1998). Challenging behaviour is also often used as a mean for the individual to exert control over his/her surroundings. For example, an individual may engage in challenging behaviour as a way to gain attention from others. Challenging behaviour may also be adopted to escape adverse circumstances, for example one might engage in behaviour that challenges to terminate a journey on a crowded bus which is causing anxiety. Challenging behaviour is also often exhibited when a person with limited communication skills is attempting to communicate that something is causing discomfort for example he/she might be in pain but is unable to verbalise this. Therefore the current understanding of challenging behaviour is that it serves a purpose, or in other words, it has a function for the individual (Hastings & Remington, 1994).

Four main categories of functions have been identified for the occurrence of challenging behaviour and these include escape, attention, gaining tangible objects and sensory/automatic reinforcement (Murphy, 1994). Challenging behaviour may be used to escape a situation or a person the individual is not comfortable with or wants to avoid; challenging behaviour, as previously mentioned, may also be used to get attention from someone. Attention may come in many forms such as talking, or hugging the individual for reassurance, but it can also assume negative connotations such as using a firm voice with the individual, who however may want attention in any way possible. Sometimes an individual may also engage in challenging behaviour to receive tangible objects: for example if an individual is constantly given an object as a means to calm him/her down, he/she will soon learn that disruptive behaviour such as shouting is followed by receiving that object and may therefore use such behaviour as a way to obtain that object. The final function category of challenging behaviour is automatic reinforcement or sensory stimulation. Some people will engage in challenging behaviour such as body rocking as they experience it as being internally reinforcing,

stimulating and as something that feels good to them. Behaviours that serve this automatic function are likely to occur across different environments, around different people and even when no one else is present (Murphy, 1994).

It has been suggested that challenging behaviour is also strongly related to the quality of the relationship between the person with ID and their carers. Previous studies have shown that there is a significant relationship between challenging behaviour and staff stress and burnout, with higher levels of challenging behaviour leading to greater negative emotions in staff as well as emotional exhaustion (Mills & Rose, 2011; Mitchell & Hastings, 2001). This is not surprising, as staff working with people with challenging behaviour are at more risk of being injured or threatened, which can cause great anxiety and cause staff to avoid clients with more severe challenging behaviour (van Oorsouw, Embregts, & Bosman, 2013). This is likely to have an aversive impact on the way that staff consequently interact and communicate with the people they support, and on the quality of care provided. A negative relationship with a member of staff might, in turn, exacerbate challenging behaviour. Indeed staff behaviour has been regarded as one of the facilitating factors in the maintenance of challenging behaviour (Hastings & Remington, 1994), through reinforcement, or failure to reinforce positive behaviours (Totsika, Toogood, & Hastings, 2008). It has indeed been proposed that challenging behaviour is not only the cause of negative interactions between people with ID and their caregivers, but it is also the outcome of this interaction (van Oorsouw et al., 2013). Therefore, it is important to reiterate that challenging behaviour is not driven by internal factors within the individual. Rather, challenging behaviour is the result of the relationship between the individual and his/her environment, including the caring environment and relationships with caregivers, who play a significant role in the daily lives of many people with ID and constitute an integral part of their surroundings. Living in supportive environments which respond to the individuals' needs, having good relationship with carers and receiving good quality support, therefore, may constitute

important factors that could somewhat reduce or prevent the occurrence of challenging behaviour.

Person-centred support in people with ID

The nature of support provided to people with ID who exhibit challenging behaviour may play a crucial role in shaping and maintaining people's behaviour. As mentioned in the previous chapter, the last few decades have seen a transformation of the care for people with ID which has been accompanied by new service philosophies that place the individual at the centre of care.

Person-centred support and individualisation have become common parlance in social and health care services and have been widely recommended for the provision of care of various service-users groups including individuals with ID. It has been widely accepted that person-centred approaches constitute the gold standard for good quality support. The essence of person-centred support is 'valuing people as individuals' (Coyle & Williams, 2001) and recognising each person's identity and individuality even when they have poor or declining cognitive abilities (Edvardsson, Fetherstonhaugh, Nay, & Gibson, 2010); care should be tailored to the person's needs as opposed to the patient-group (Brooker, 2003) and services should be moulded around the individual rather than the individual adapting to a universal 'one size fits all' frame. Person-centred support entails thinking about services in a manner which involves starting from the person rather than the service which in turn should be adaptable, dynamic and changing according to the needs of its users (Dowling et al., 2006).

The person-centred approach has been widely recommended as best practice and adopted by social policy. In the Government's report *Putting People First* (Department of Health, 2007a) it was emphasised how each individual should have the right to high quality personally tailored services and individually tailored support packages. Similarly in *Valuing People Now* (Department of Health, 2009) it is emphasised that services should adopt person-centred approaches and that each individual should have

personalised support plans. It has been suggested that more individualised, person-centred services offer a greater opportunity for independence, community integration and a better quality of life (Heller, Miller, & Factor, 1998). Person-centred approaches take into consideration the needs, desires, interests, preferences, understandings and lifestyle choices of individuals and put them at the centre of care, providing opportunities for decision-making and promoting inclusion, independence and empowerment (Charalambous, Chappell, Katajisto, & Suhonen, 2012; Dowling et al., 2006).

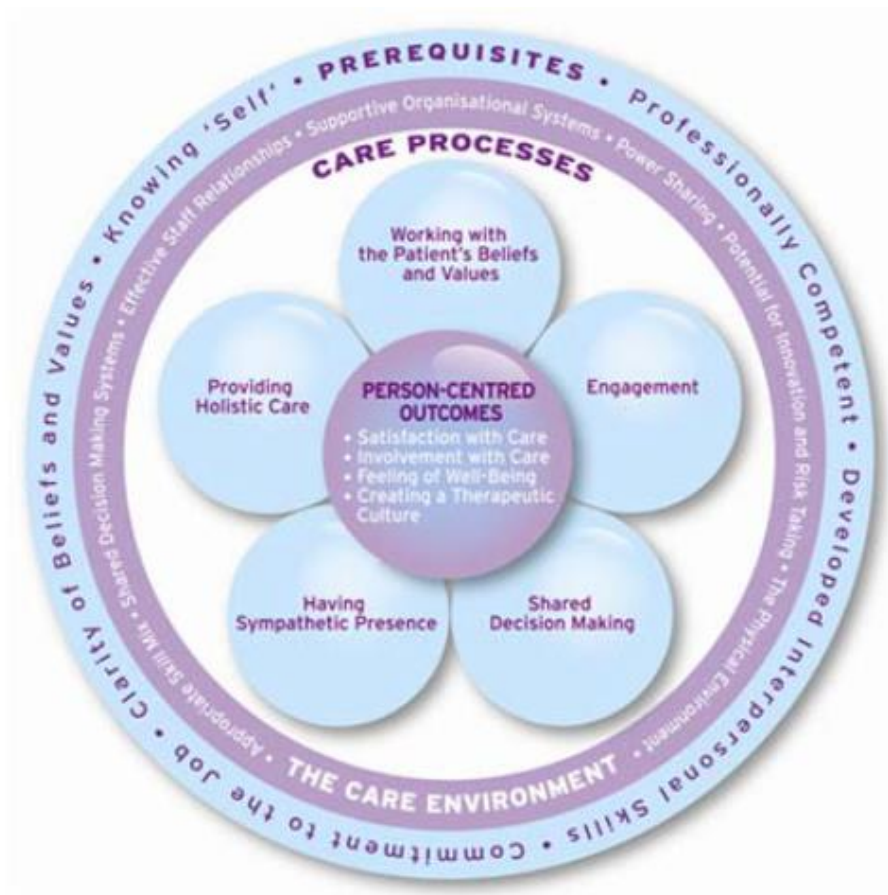
Although there is no single approach to working with someone in a person-centred manner, White, Newton-Curtis, and Lyons (2008) identified six dimensions that constitute person-centred support. These include personhood, knowing the person, autonomy, choice, comfort care and nurturing relationships. Similarly De Silva (2014) reported that the most common elements of person-centred support reported in the literature are:

- Knowing the person and recognising their individuality
- Taking a holistic approach to assessing needs and providing care
- Recognising service-users' expertise in their own care
- Choice and autonomy recognition and promotion
- Accessible services
- Continuous integrated care
- Supportive staff able to engage and communicate effectively with those for whom they provide care.

In the field of nursing McCormack and McCance (2010) defined person-centredness as “an approach to practice established through the formation and fostering of healthful relationships between all care providers, service users and others significant

to them in their lives. It is underpinned by values of respect for persons, individual right to self-determination, mutual respect and understanding. It is enabled by cultures of empowerment that foster continuous approaches to practice development” (p.13). The authors developed a theoretical framework of person-centeredness which includes four constructs *Prerequisites* (necessary attributes of nurses), *The Care Environment* (context in which support is delivered), *Person-centred Processes* (delivery of support) and *Outcomes*. A visual representation of the Person-Centred Nursing Framework is illustrated in Figure 2.1 (McCormack and McCance (2010)

Figure 2.1 Person-Centred Nursing Framework



It is acknowledged that the essence of person-centred support is building a partnership between the service-user and the caregiver, placing great emphasis on mutual trust, respect and understanding (De Silva, 2014; McCance, McCormack, & Dewing, 2011).

White et al. (2008) stated that knowing the person for whom care is provided is essential for person-centred support and the understanding of behaviours such as those that challenge. How well carers know the person they provide care for, how effectively they communicate with them and how much they provide opportunities for autonomy and self-determination is likely to have a great impact on the individual. The way caregivers behave plays a crucial role in the quality of care provided and it has been suggested that staff members are indeed one of the most important elements of the care system (Rose, 2011).

In the previous chapter I described how for people with ID, PCP has often been considered as an essential approach to promote change in their lives, but how, from a practical point of view, in PCP great emphasis is placed on the presence of individualised support plans for each care-recipient aimed at improving their quality, which however, do not always translate into action (implementation gap) rendering PCP a mere 'paper exercise'

Person-centred action practices

There are other person-centred approaches which place less emphasis on planning and more on action: Positive Behaviour Support (PBS), Active Support, Augmentative and Alternative Communication, The National Autistic Society's SPELL framework for supporting people on the autistic spectrum are all person-centred practices which have been promoted to provide support for people with ID and which can be used as means to actualise the goals set out in the person-centred plans.

Unfortunately, the existence of several approaches has often led people in services to view them as separate entities from which to pick from. These approaches however should not be considered as alternatives, they should be seen as complimentary practices to be used together (Mansell & Beadle-Brown, 2012). Furthermore it has been observed that their implementation is not wide-spread in services for people with ID and most often they have not been adopted in routine practice by front-line staff.

These approaches require extensive training and in order to achieve successful outcomes they have to be adopted consistently by all members of the support team (Mansell & Beadle-Brown, 2012).

Person-Centred support and challenging behaviour

Although person-centred support has been advocated in the National Institute for Health and Care Excellence for the management of challenging behaviour and ID guideline (NG11; NICE, 2015), there is evidence that person-centred practices are not widely implemented across services. Frontline staff who are the most involved in people's everyday care, often do not have the formal training to undertake the difficulties that challenging behaviour presents. Dealing with challenging behaviour in people with ID often requires a high degree of skill which is not pervasive in paid support staff. One of the consequences of this is the management of challenging behaviour with widespread use of psychotropics, mainly antipsychotics even in the absence of a diagnosis of mental illness (Bowring, Totsika, Hastings, Toogood, & McMahon, 2017; Sheehan et al., 2015). Nevertheless there is no confirmatory evidence for the use of medication for the successful management of challenging behaviour (Deb et al., 2014; Deb, Sohanpal, Soni, Len, & Unwin, 2007; Tyrer et al., 2009) and therefore further investigation into person-centred practices is warranted.

Positive Behaviour Support

The person-centred approach which has been specifically developed for the reduction of challenging behaviour in people with ID is PBS; research has shown that this approach is effective and following its implementation there has been evidence of reduced challenging behaviour (MacDonald & McGill, 2013).

PBS has its origins in Applied Behaviour Analysis (ABA) and it is a behaviour management system aimed at understanding what maintains challenging behaviours. Similarly to ABA, PBS works by modifying behaviour through the manipulation of

triggers and reinforcers but in contrast to ABA aversive techniques and punishment are not used. PBS is a multi-component intervention which reflects the notion that challenging behaviours are often determined by multiple factors and manifested in multiple forms (Allen, James, Evans, Hawkins & Jenkins, 2005). It is an intervention based on the assumption that challenging behaviours are not caused solely by the individual's internal drivers but are influenced by the environment surrounding the individual, and indeed some of the components of PBS focus on ecological changes and are aimed at influencing the interaction between the individual and the environment. This can be achieved by intervening on the mismatches between the person's needs and his/her physical and social environment for example by teaching new skills or more appropriate responses which serve the same function as the challenging behaviour but may be more socially acceptable. Other elements of PBS are the use of functional assessments, use of contingent and non-contingent reinforcement, use of proactive and reactive strategies and emphasis on antecedent control (MacDonald & McGill, 2013). The aim of PBS is not only the reduction of challenging behaviour in people with ID but it is also to improve the quality of life of both the individuals and those who provide support for them, removing the barriers that constitute an impediment to a better quality of life and doing so by minimising aversive effects (LaVigna, Willis & Foreman, 2012).

Despite the fact that there is evidence demonstrating that when implemented with fidelity, PBS can be really effective in successfully managing challenging behaviour, it has been shown that in actual practice it is not widely implemented and it has been estimated that only between 1 and 20% of people who would benefit from such intervention actually receive any form of behavioural support. Even in the context of well-resourced research studies on the implementation of PBS has proven to be difficult. For example in a recent multi-centre randomised controlled trial investigating the effectiveness of PBS, it was found that approximately only 30% of people allocated to the intervention arm of the study actually received the intervention. Only 33 PBS

plans were formulated for the 108 participants in the intervention arm, and all of the plans were rated as weak by an independent reviewer (Hassiotis et al., in press).

Reasons that may contribute to difficulties in implementing PBS widely are the scarcity of skilled staff trained in the competencies of PBS (assessment, functional analysis, application of behavioural principles and evaluation), staff shortages or high staff turnover and the labour-intensive nature of PBS which requires a systematic and coherent approach as well as substantial resources; additionally the fact that, despite the guidance advocating the use of PBS (e.g. *Positive and proactive care: reducing the need for restrictive interventions*; Department of Health, 2014), its implementation is not a statutory requirement in community settings, and this may also constitute a reason why it is not commonly adopted (Allen et al., 2005).

Since this approach is not routinely used in practice, it is useful to consider whether other person-centred approaches which may be more reflective of everyday support provided by direct carers are associated with challenging behaviour in people with ID.

Other person-centred practices

The research to date that has considered other person-centred approaches has not found consistent associations between person-centred support and challenging behaviour.

As previously discussed in Chapter 1, although some studies reported improvements in participants' challenging behaviour following the introduction of PCP (Black et al., 2010; Magito-McLaughlin et al., 2002; Truesdale-Kennedy et al., 2006), a study by Robertson et al. (2006), which investigated the longitudinal effect of PCP on a variety of outcomes for people with ID, reported conflicting findings; counter-intuitively the study found that following the implementation of PCP participants displayed increases in emotional and behavioural difficulties and a reduction in positive and pro-social behaviour compared to baseline levels. The authors argued that this unexpected finding could have possibly been due to the fact that PCP promoted an increased participation in social and

community-based activities, the novelty of which might have constituted a source of anxiety for participants, leading to a deterioration of their behaviour.

Studies looking at the effect of Active Support on challenging behaviours have also produced inconsistent results. Active support is a person-centred model of care which places importance on participation in meaningful activities and engagement, and through the use of appropriate support and communication techniques enables successful participation in all aspects of an individual's life. One of the core principles of Active Support is the enabling relationship between the person providing care and the person receiving it. Care-recipients are supported to successfully participate in meaningful activities and relationships in order to gain more control and independence in their lives (Mansell & Beadle-Brown, 2012).

Research from Smith, Felce, Jones and Lowe (2002) and Jones et al., (2001) found no effect of Active Support on challenging behaviour; other studies however suggested that Active Support may have the potential to reduce challenging behaviour. A study by Koritsas, Iacono, Hamilton and Leighton (2008) found an overall decrease in challenging behaviour measured by the Total Problem Behaviour Score of the Developmental Behaviour Checklist for Adults (Einfeld, Tonge, & Mohr, 2003) at six months after staff training compared to baseline levels. Challenging behaviour had however increased immediately after training. A similar pattern was found for a specific subscale of challenging behaviour, namely disruptive behaviour (i.e. has tantrums, irritable) which showed increases post-training but an overall decrease at 6 months follow-up. A significant linear decrease from baseline to 6 months follow-up was observed for other behaviour subscales, specifically anxiety/anti-social behaviour (e.g. lights fires, panics) and self-absorbed behaviour (e.g. pica, hums). The other forms of challenging behaviour reported in the study (communication disturbance (e.g. talks too much), social relating (e.g. loner, shy) and depressive (e.g. withdrawn)), however, showed no significant change following the implementation of Active Support. Beadle-Brown, Hutchinson, and Whelton (2012) also explored the impact of the

implementation of Active Support on challenging behaviour. The study did not find a significant reduction of overall challenging behaviour following the implementation of Active Support. A statistically significant reduction, however, was observed for repetitive, stereotypical and self-stimulatory behaviours.

The evidence from these studies suggests that Active Support has the potential to reduce challenging behaviour, however this may only apply to specific sub-types of challenging behaviour and further research is needed to demonstrate the effectiveness of this person-centred practice. Furthermore, Active Support has been primarily investigated in well-resourced, controlled, research studies. Nevertheless, although it has been demonstrated that Active Support does not require more staff and its implementation does not cost significantly more, in order to achieve successful outcomes it does require skilled staff, as the intervention is not necessarily easy to implement (Beadle-Brown et al., 2016). Similarly to PBS and PCP it does not appear that Active Support is widely adopted in everyday care and for example, from a randomly selected sample of services from Care Quality Commission registration lists, it was found that only 12% of people received good Active Support consistently (Beadle-Brown et al., 2016). Given the recorded low rates of the uptake of this intervention, there is a need to further investigate this approach in pragmatic conditions.

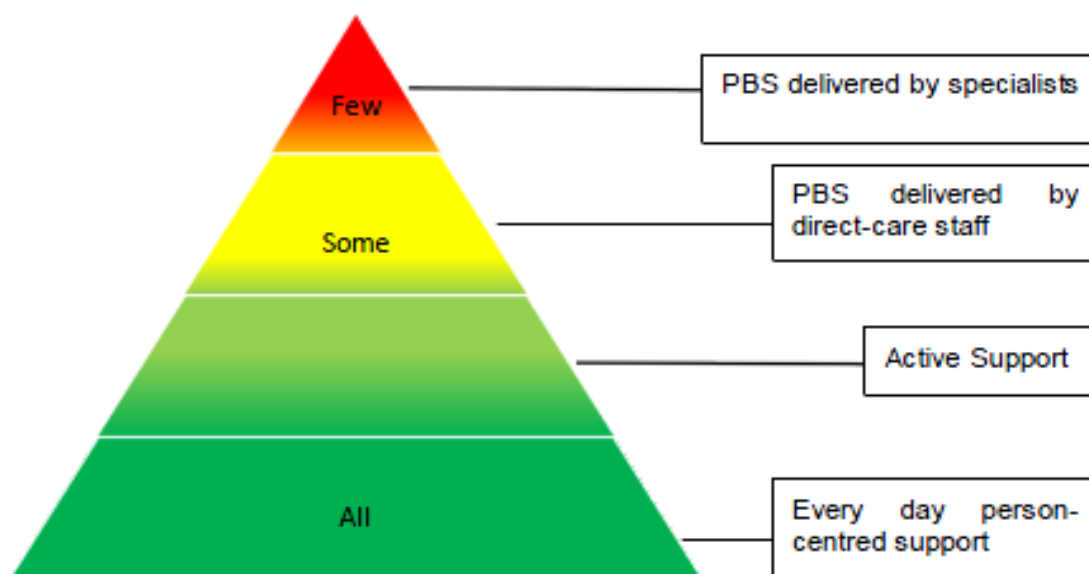
Evidence from other research studies has shown that providing care which includes at least some elements central to person-centred support, can reduce behaviour that challenges and for example Felce and Perry (1995a) found that there was a significant inverse relationship between staff:resident interactions and challenging behaviour, with those individuals involved in more interactions with staff displaying less challenging behaviour; in a later study it was found that in community housing where residents had benefited from improvements in activities, community participation and assistance from staff compared to those in traditional services, over time there were also reductions in challenging behaviour (Felce et al., 1998). It must be noted however, that all these

variables were also significantly related to residents' adaptive behaviour, a known predictor of challenging behaviour, and therefore these results do not provide evidence that there is a direct relationship between elements of support variables and challenging behaviour. Nevertheless the results are indicative of a possible relationship which is worth exploring further in the current policy climate which places great emphasis on person-centred approaches.

Intuitively, those individuals who receive care in an environment which promotes person-centred support by staff who know them well and recognise their uniqueness, communicate effectively with them and provide them with more opportunity for autonomy and choice, should be less likely to engage in severe challenging behaviour. Knowledge of the individual and communication are both important aspects of person-centred support and can provide a reflection of the quality of care provided. Knowing the care-recipients facilitates the understanding of needs and behaviours, including challenging behaviours, especially for those individuals with communication difficulties.

Furthermore, if carers adopted the principles of person-centred support more widely in everyday practice the need for more specialist input for issues such as challenging behaviour would be reduced and needed by fewer people as represented in Figure 2.2.

Figure 2.2 Pyramid of care



A recent study by McGill et al. (unpublished) which tested a system-wide intervention focused on improving the quality of support rather than “treating” challenging behaviour at the individual level found significant decreases in challenging behaviour in the intervention arm compared to the control group. The findings suggest that improving the quality of support and intervening directly at the organisational level rather than the individual level can have a beneficial impact on challenging behaviours. The study however has not yet been published and specific details of the intervention are not available.

Beadle-Brown et al. (2015) argued that there is a need for firmer evidence on the nature of support available for people with intellectual disabilities and the impact of such support on outcomes. It is one of the aims of this thesis to explore whether receiving support in a person-centred fashion by non-specialist staff has any association with the occurrence and severity of challenging behaviour in people with ID.

Defining and measuring person-centred approaches

Although the concept of person-centred support is regarded as crucially important and has been broadly accepted as the way forward in care provision, a unique and robust definition of the concept does not exist and in fact there are diverse perceptions of what person-centred support actually entails (Suhonen, Välimäki, & Leino-Kilpi, 2002).

In the field of ID person-centred approaches have been studied in the context of interventions such as Active Support and PBS however, as previously mentioned these interventions are not consistently implemented in everyday practice and they require extensive skills and training.

Although a wealth of measures have been developed to measure features of person-centred support, De Silva (2014) argues that there is no best measure that covers all aspects of this multi-faceted concept and there is no agreement over which tools are most appropriate and reliable to measure this construct. Whilst there are a few scales

which measure the concept holistically (e.g. Individualised Care Scale, Measure of Processes of Care, Person-Centred Care Assessment Tool and more recently the Person-Centred Practice Inventory-Staff ; Slater, Mccance, and McCormack, 2017), these are not specific to ID populations. To the researcher's knowledge no non-observational measures specific to people with ID exist to measure the construct of every day person-centred support quantitatively, and this may be due to its ambiguous nature. Dewing and McCormack (2017) indeed argued that one of the difficulties of measuring person-centredness is the lack of a specific definition of the concept.

In the field of research in ID the Active Support Measure (ASM) (Mansell & Elliott, 1996) has been commonly used to measure the quality of support in residential environments. The measure however, although quantitative, is observational and cannot be self-administered. Completing the ASM requires periods of direct-observations and this can be time-consuming, expensive, and not always feasible in the context of research.

There are nonetheless many instruments that measure components of person-centred support such as shared decision-making and communication, though there is no consensus as yet about an emerging best approach and no measure has been shown to be inherently better than the rest to measure this construct. Chappell, Reid, and Gish (2007) argued that a valid and reliable holistic measure of person-centred support is necessary in order to be able to measure scientifically whether this approach to care is indeed associated with positive outcomes In Chapter 3 of this thesis the issue of measuring person-centred support quantitatively by adapting measures previously used in the field of older adults with dementia is considered.

Choice

So far person-centred support has been considered as a holistic concept, but as previously discussed person-centred support is characterised by various components; one which has received much attention by researchers in the field of ID, and on which

particular importance has been placed, is choice. The next section describes how choice has thus far been integrated in the care of people with ID and to what extent it has been made available to this population

The importance of choice and its availability for people with ID

Choice has been regarded alongside inclusion and independence as one of the three quality of life domains which should guide policy and practice (Beadle-Brown, 2006) and indeed in *Valuing People Now* (Department of Health, 2009) it has been emphasised that one of the primary policy objectives of the transformation strategy of care services entails providing more opportunity for choice and autonomy for people with ID. Choice-making is regarded as a right for every human being and it should be an essential part of everyone's life, with choice being considered a crucial dimension of quality of life (Kearney, Durand, & Mindell, 1995a).

It has been argued that as a consequence of the process of deinstitutionalisation and the move to community based settings people with ID have been given the opportunity to exercise more control over their own life and have been given more opportunities to make choices (Wehmeyer & Bolding, 1999). Indeed it has been found that individuals living in smaller community homes typically enjoy more choice than residents in segregated environments, with those living in settings with fewer residents and greater individualisation exercising the greatest levels of choice (Emerson et al., 2001; Stancliffe, 2001; Stancliffe & Parmenter, 1999). However, in comparison to people without ID, the opportunity for choice and self-determination is still disturbingly low for people with ID and service-users often remain passive recipients of care with little or no control (Stancliffe, 2001). Furthermore, it has been observed that choices regarding major life decisions such as residential placement, staff appointment, housemates, employment, etc. are practically non-available and opportunities to make choices are provided more so in daily routines such as deciding what to wear, what to do or what to eat (Robertson et al., 2001; Stancliffe, 2001; Stancliffe & Parmenter, 1999). Wehmeyer

and Bolding (1999) found that people living in non-congregate settings had more opportunities for choice and autonomy than their peers in congregate settings. Participants in the study were matched by IQ thus minimising the impact of personal characteristics on the observed differences. The authors concluded that there may be certain characteristics within different living environments which may be more conducive to choice-making, as differences were observed even when controlling for variables such as intellectual functioning.

Opportunities for choice are also largely related to level of disability and adaptive behaviour, with people with milder intellectual impairment being consistently presented with more choice opportunities compared to their more disabled counterparts (Lakin et al., 2008; Ticha et al., 2012). Those with greater communication ability are more heavily involved in decision-making whereas those with more severe communication difficulties are often excluded from having input on decisions affecting their life and many decisions affecting their daily living are made *for* them (Ticha et al., 2012). Previous research has however shown that given the right context and right support, even people with more severe intellectual disabilities are capable of making choices and communicating their preferences (Kern et al., 1998). Picture communication systems or systematic preference assessment provide examples of approaches which may be used to identify choices and preferences among individuals with communication impairments (Reid, Everson, & Green, 1999).

Unfortunately, it is the case that many people with ID have been passive recipients of care for great part of their life and have never been supported to make choices and therefore do not understand the concept or have the means to do so. Moreover, people with ID, especially those who have had long term stays in segregated or hospital care may have not been exposed to sufficiently diverse environments and activities to develop preferences and explore opportunities for personal growth. The limitations

posed by their own experiences may render the process of choice-making hard to understand and practice (Dowling et al., 2006).

Choice and challenging behaviour

It has been suggested that providing individuals with choice opportunity over their daily matters could be a contributing factor for the prevention of challenging behaviour as individuals will be able to exert more control over their surroundings which often provide triggers for behaviour that challenges. Studies investigating the relationship between choice opportunities and challenging behaviour, have however produced mixed results and a clear understanding of this relationship has not been achieved. In a study by Stancliffe, Abery, and Smith (2000), for example, it was found that there is clear relationship between an individual's challenging behaviour and his/her level of personal control over what occurs in their life, with those individuals displaying less challenging behaviour exercising more control regarding choices and decisions of events occurring in their everyday life. The study however did not strictly investigate the relationship between opportunities for choice-making and challenging behaviour, but in fact used level of challenging behaviour as a predictor of personal control and self-determination. Although these concepts incorporate choice-making as a sub-component they also include other components such as self-regulation, social and communication skills, self-esteem, etc. and therefore the inverse relationship which was found with challenging behaviour cannot be attributed to opportunities for choice alone (Stancliffe et al., 2000). Hatton et al. (2004) found a moderate and consistent inverse relationship between choice and challenging behaviour, nevertheless they did not control for adaptive behaviour in exploring the relationship and therefore the results may be somewhat misleading, as research has consistently found that adaptive behaviour is an important predictor of choice-making. In another study by Emerson et al. (2001) in which choice-making was assessed between different residential settings no significant association between choice and challenging behaviour was discovered. Whereas choice was related with other factors such as social network and number of

other residents with intellectual impairment, a significant association with challenging behaviour was not reported.

In studies investigating the relationship between choice availability and aspects of challenging behaviour such as self-injury and aggression, contrary to what was expected, no inverse relationship was found between the variables (Kearney, Bergan, & McKnight, 1998; Kearney, Durand, & Mindell, 1995). Strikingly Kearney et al. (1995a) actually found that more choice availability was positively associated with increased inappropriate speech (e.g. swearing) and inappropriate social behaviour (e.g. stealing, showing lack of consideration for others). Further contrasting evidence comes from other cross-sectional studies which have explored the link between choice and challenging behaviour. Lakin et al. (2008) for example found that in a sample of 2948 individuals with ID, self-injurious and disruptive behaviours were negatively associated with everyday choice-making and support-related choice (choices regarding support received e.g. staff employed), with less challenging behaviour predicting more choice-making. The relationship between everyday choices and challenging behaviour however became non-significant when other variables such as residential settings were introduced to the model suggesting that the relationship may be somewhat weak. In a similar study by Ticha et al. (2012) the presence of challenging behaviour was found to constitute a significant predictor of everyday related choices and this was sustained even when additional variables such as level of ID and communication ability were accounted for. The relationship between challenging behaviour and support-related choices on the other hand was weaker and it was only significant when other variables were not taken into account. The study suggests that challenging behaviour is related to everyday choice-making, and from the results of this study it could be interpreted that when people with ID are provided with more choice opportunities in their daily lives they are less likely to engage in challenging behaviour. However, it could also be the case that those individuals who engage in less challenging behaviour are given more opportunities for choice-making, whereas those who engage in more challenging

behaviour may face more restrictions from staff and are provided with less opportunities to exercise choices. A further explanation of the relationship between these variables can be that those individuals who are less skilled to make choices or are less able to understand the concept of choice may use more socially unacceptable methods i.e. adopting behaviours regarded as challenging to express their preferences (Stancliffe et al., 2000). Because of the correlational nature of this and other studies, no definite inferences about causality can be drawn from the results, and therefore it is impossible to determine whether improving choice can ameliorate challenging behaviour.

Smaller case studies however have reported that providing more choice opportunities on a daily basis can reduce levels of challenging behaviour in people with ID. For example in a review of the literature of choice interventions (Kern et al., 1998) identified a study showing a direct link between choice and challenging behaviour: When choice was provided to conduct an activity, no challenging behaviour was manifested whereas in the no choice-direct prompt condition (participant being told to perform activity), protests and challenging behaviours were observed (Bambara, Koger, Katzer, & Davenport, 1995). This finding suggests that promoting choice could be a possible way to avoid the manifestation of challenging behaviour, and this was achieved simply by asking choice questions as opposed to giving direct instructions. The results of this case study however are not generalisable to the rest of the population as it reports results based on only one participant, therefore even though the findings provide an indication of a possible link between choice availability and the non-occurrence of challenging behaviour they must be interpreted with much caution. In another study implementation of a choice plan for twenty-one individuals with ID in community-based residential facilities also resulted in reductions of the frequency and severity of challenging behaviour (Ip, Szymanski, Johnstonrodriguez, & Karls, 1994). The study had several limitations (e.g. small unrepresentative sample, observer not blinded to intervention arm, *p* value set at 0.1) and the authors warranted further replications,

however they argued that their study provided further evidence for the potential of choice provision for the reduction of challenging behaviour.

As shown, even though there has been significant interest in exploring the association between choice and challenging behaviour, no clear picture has emerged as the evidence supporting the link has been somewhat contradictory, thus warranting further research in order to clarify this relationship.

Limitations of previous research

From the results of previous research no consistent association has emerged between choice-making and challenging behaviour. The presence of mixed findings could be due to the fact that some of the studies investigating the relationship between these variables had small sample sizes and thus not enough power to detect the relationship, which to begin with may be somewhat modest. In fact, even in larger studies such as Lakin et al. (2008), the relationship between choice and personal characteristics such as challenging behaviour was weak with challenging behaviour only explaining 1% of the variance in everyday choice-making. However the choice measure used in that study, as well as in the Ticha et al. (2012) study, was very brief, with the everyday choice subscale only comprising three items (“Who decides your daily schedule?”, “Who decides how you spend your free time?”, “Do you choose what to buy with your spending money?”). The measure therefore does not provide a comprehensive picture of everyday choice-making and therefore associations between this construct and other variables should be interpreted with caution. The presence of challenging behaviour was also not assessed with a comprehensive, valid and reliable measure and only four aspects of problematic behaviour were assessed and these were defined as challenging behaviour, self-injury, disruptive behaviour and uncooperative behaviour; such behaviours were scored as 0 (no support needs), 1 (some support needs) or 2 (extensive support needs) in terms of their severity, but did not provide a comprehensive picture of individuals’ challenging behaviour. The measures used in

these studies may have not been appropriate and therefore it is difficult to draw definite conclusions regarding the existence of a relationship between choice and challenging behaviour in people with ID. Using more extensive and comprehensive measures of everyday choice-making and challenging behaviour would have been more likely to yield a true relationship.

Another factor to be considered is that earlier studies might have been conducted with participants who had recently moved from institutions where choice opportunities were typically not available and thus individuals had become accustomed to rigid routines over which they had little or no control. A sudden opportunity for choice given to people who had not previously experienced such a circumstance, could actually provoke anxiety due to the unfamiliarity of the situation or the perceived lack of skill to make a decision based on choice, and this could manifest itself through challenging behaviour.

As previous studies have not clearly elucidated the nature of the relationship between choice and challenging behaviour in people with ID, I will further explore this relationship in Chapter 4 by using more appropriate measures in a relatively large sample size. If a relationship between choice availability and challenging behaviour does indeed exist, there are several practical advantages to promote and embed choice within daily routines. Promoting choice is quite straightforward and simple, does not require extensive training and can be implemented within the service-users' living environment (Kern et al., 1998). Small every day choices are unlikely to have major cost implications or challenge the system of care and it should therefore be easy to act upon these choices and for staff to provide support in their implementation. It is often the small choices regarding everyday activities that really enhance the life of an individual (Parley, 2001).

Conclusion

In his chapter I have provided an overview of the constructs which are central to the thesis a summary of which can be found in Box 2.1.

As described approximately 10-15% of people with ID display challenging behaviour which can have drastic negative consequences in their lives. Interventions aimed at reducing challenging behaviour such as PBS are not widely implemented as they require substantial skills and resources and it is estimated that only between 1-20% of people who would benefit from such interventions, get any sort of behavioural support.

Since it is commonly accepted that challenging behaviours are the product of an interaction between the individual and his/her surroundings, it is intuitive that the quality of the non-specialist support received in their everyday life plays an important role in shaping and maintaining or preventing challenging behaviour.

Person-centred support has been recognised as the gold-standard of support for people with ID however in the field there are no quantitative non-observational measures of this construct which makes it hard to investigate whether the support received by people with ID in their everyday lives by non-specialist staff is indeed person-centred and if it is associated with other variables such as challenging behaviour.

In the following chapters I aim to explore person-centred support in adults with ID and challenging behaviour supported by paid carers in community settings in more detail. Firstly I address the issue of measuring this construct quantitatively by adapting measures previously used to measure person-centred care in older adults with dementia (Chapter 3). I also include a measure of choice which has been considered as a crucial aspect of person-centred support and has been widely studied in people with ID. Secondly I explore the relationship between the adapted measures of person-centred support with challenging behaviour and other variables in a cross-sectional study (Chapter 4). I then describe the results of direct-observations of 18 individuals in order to provide a snapshot of the nature of the support received by individuals in their homes (Chapter 5). The observations also triangulate the results of the quantitative study and provide an additional perspective to the information collected using the carer

self-report questionnaires. Finally I conclude with a general discussion of the various chapters bringing together the findings from the cross-sectional and observational studies (Chapter 6).

Box 2.1 Summary overview

- Challenging behaviour affects approximately 10-15% of people with ID
- Challenging behaviour is the product of an interaction between the individual and the environment
- Carers and the support provided play a crucial role in reinforcing/maintaining challenging behaviour
- Person-centred support has been advocated as best practice in the care of people with ID
- There are various person-centred approaches such as PBS and Active Support, but these are not widely implemented in everyday care
- PBS is the recommended approach for managing challenging behaviour however it requires skilled staff, extensive training and there are difficulties in its wider implementation
- There are no non-observational quantitative measures of everyday person-centred support for people with ID
- It is intuitive that everyday person-centred support may be associated with challenging behaviour but this needs to be explored
- Person-centred support in everyday practice may reduce the need for more specialist input for challenging behaviour
- Choice is an important domain of person-centred support which has been more widely researched in people with ID
- There is also no definitive relationship between choice and challenging behaviour.

Chapter 3. Exploring the suitability of the person-centred support measures in the present sample

Introduction

(See Appendix B1 for published version of the Resident Choice Assessment Scale adaptation)

As described in the previous chapter available measures of person-centredness, are proxy measures and there are very few holistic measures of person-centred support which can be administered to non-specialist staff in every day care. In a review of person-centred support measures, De Silva (2014) did not identify any tool specifically developed to measure person-centred support for people with ID. The majority of the tools available measure person-centred support for older people with dementia in hospitals or care homes. The principles of person-centred support are however transferable across social care and therefore, in the of absence reliable scientific measures of person-centred support in the field of intellectual disabilities, one of the aims of the present chapter was to adapt staff-completed person-centred support measures which were originally developed for people supporting older adults with dementia, and explore their suitability for use with paid carers of people with ID living in supported living or residential accommodation.

Due to the difficulty in measuring the concept of person centred support in its totality, the present study used two different general measures of person-centred support in order to capture a more comprehensive picture of the support provided by the paid carers taking part in the research. After reviewing the measures of person-centred support available, two measures were chosen to be included in the present project: i)

Chappell, Reid and Gish (2007)'s Individualised Care instrument and ii) Edvardsson, Fetherstonhaugh, and Nay (2011)'s Tool for Understanding Residents' Needs as Individual Persons (TURNIP). The Individualised Care instrument captures aspects of individualised care pertaining to the relationship between the service-user and the caregiver and the quality of this relationship. These aspects include:

- How well carers know the service-users
- How much opportunity for autonomy is provided to the service-users
- How well caregivers communicate with service-users and with other staff members regarding the service-users;

The TURNIP provides an overview of the extent to which caregivers provide care in a person-centred manner. Neither of these measures has ever been used with carers of people with ID.

With regards to choice, on the other hand, in the last few decades a number of instruments have been developed to measure its availability for people with ID in different living environments (Hatton et al., 2004; Kishi, Teelucksingh, Zollers, Park-Lee, & Meyer, 1988;; Stancliffe & Parmenter, 1999); one such example is the Resident Choice Assessment Scale (RCAS; Kearney et al., 1995a) which was developed to measure choice availability for people with ID living in various residential settings, including larger institutions. The RCAS can be self-completed by direct-care staff, which contrasts to measures which are more suitable for administration via interview (Hatton et al., 2004; Stancliffe & Parmenter, 1999) and covers aspects of choice surrounding various everyday activities. The RCAS has demonstrated acceptable psychometric properties.

The two decades following the introduction of the RCAS have seen a changing landscape for the provision of care for people with ID, with the closure of large institutions and the move to community settings. In countries such as the United

Kingdom (UK), United States (US), Australia and Sweden ordinary housing in the community is now widely advocated as the best model of support for people with ID. In the US the Developmental Disabilities Assistance Bill of Rights Act (DD Act) has been influential to the advent of community-based supports and in the UK the Government has been committed to ensuring that the number of people in large scale residential care is dramatically reduced and that no one is inappropriately living in a hospital setting (Department of Health, 2007b, 2012). The rationale underpinning this shift in the provision of care for people with ID is the promotion of a better quality of life and better outcomes, which are thought to be better achieved in smaller community supported living services (Department of Health, 2001; Emerson, et al., 2001). Since nowadays the majority of people with ID in countries such as the UK and USA reside in the community, the RCAS in its original form may not be suited to the current context as some of its items which reflect past practices in congregate institutional settings may not be relevant in community living in the present day. The second aim of chapter was to evaluate the RCAS in community living environments and to review and adapt it for use in the current care context

Aims

- To adapt measures of person-centred support used in previous research in the field of old age care by conducting factor analyses in order to modify them for use with people with ID living in the community.
- To update a measure of choice which was developed three decades ago for use in the current context of care.

The following section describes the steps taken to explore the psychometric properties and factor structure of each measure. The procedural steps common to all measures are presented first. These are followed by detailed analysis specific to each measure, with the measures of person-centred support presented first, followed by the measure of choice.

Method

As previously mentioned, the present study is an addition to a larger randomised two arm multi-centre trial investigating the clinical and cost-effectiveness of training health professional in PBS techniques for the reduction of challenging behaviour in people with ID (Hassiotis et al., 2014). In the study, PBS was delivered in the community by the participating trained health professionals and the aim of the study was to compare outcomes between people receiving PBS and those receiving treatment as usual (TAU). The primary outcome of the research was the reduction of challenging behaviour which was measured at 6 and 12 months following initial baseline assessment. Other outcomes included participation in community activity, carer burden, use of health services and medication intake. Participants were recruited from nineteen community ID services located across several regions in England (London, Leicestershire, Kent, Surrey, Bradford, Coventry and Warwickshire) which cover urban, semi- rural and rural areas.

Participants and settings

A cohort of 133 paid carers of people with ID already participating in the PBS study from several regions in England were invited to take part. The carers supported adults with ID living in the community in supported living arrangements, typically accommodating between one and seven people in ordinary housing, and residential care homes, the largest of which had capacity for a maximum of 62 residents. Participants were drawn from a wide range of agencies and care providers to minimise the possibility that the results would be affected by their policies and practices. Carers were excluded if they did not take part in any of the PBS study assessments.

Inclusion criteria

a) Carers: Paid carers who took part in the PBS study and who agreed to take part in future studies.

b) Service-users: Mild to severe ID; aged 18 years and over; total screening Aberrant Behaviour Checklist (Aman, Singh, Stewart, & Field, 1985) score of at least 15 (indicates a degree of challenging behaviour occurring at least weekly including verbal or physical aggression, hyperactivity, refusal to attend activities, non-responsiveness that requires professional input).

Exclusion criteria

a) Carers: Paid carers who did not take part in any of the assessments for the PBS study

b) Service-users: primary clinical diagnosis of personality disorder or substance misuse; relapse in pre-existing mental disorder; decision by clinical team that a referral to the PBS study would be inappropriate, e.g. there is an open complaint investigation.

Measures

Demographics questionnaire. Demographic information of participants collected during the PBS study was used in the present study. Information regarding age, gender, level of ID (determined by the Wechsler Abbreviated Scale of Intelligence; Wechsler, 1999), and adaptive behaviour (measured by the Short form Adaptive Behaviour Scale; Hatton et al., 2001) was used for the service-users; information regarding age, gender, years of caring for people with ID, length of acquaintance with service-users and educational qualifications was used for the carers.

Information was also collected on the type of accommodation where participants lived/worked. This consisted of either residential care homes or supported living (individual/group). Accommodation is classified as supported living when personal care is provided under separate contractual agreements to those for the person's housing. Supported living housing services are not required by law to register with Care Quality Commission (CQC). On the other hand accommodation is classified as residential care when housing and support are combined and come under the same provider and the facility is registered with CQC.

Individualised care (IC) (Chappell et al., 2007). The IC is constituted by a group of brief non-observational staff based-measures of individualised care developed to capture three important domains: knowing the service-user, service-user autonomy and choice, and communication. Each domain is measured by a separate scale and a distinction is also made between communication with other members of staff and communication with service-users. The scales are described hereafter:

- IC-KNOW: measures how well the member of staff knows the person they provide care for, what her/his needs, likes, preferences and personal patterns are. The scale consists of thirteen items each rated on a four point Likert scale ranging from 1 (strongly disagree) to 4 (strongly agree) and examples include “I have a good understanding of the residents I care for” and “I know what the residents I care for like”.
- IC-AUTONOMY: measures how much autonomy and opportunities for choice service-users are given. The scale consists of fifteen items rated on a five point Likert scale (1= very frequently; 5 = never) asking how often staff provide service-users with the opportunity for choice in their day-to-day life for example over activities or meals, and how often autonomy is promoted (e.g. “Feel that you have enough time to allow residents to do things for themselves”; “Feel that you are able to allow the residents that you look after to make decisions for themselves”).
- IC-COMMUNICATION-SR (staff-to resident): the scale is a seven-item measure of communication effectiveness between the paid carer and the person who they support. Carers are asked to rate how often (1=never to 4=always) they used each approach in the past seven days (e.g. “Talk to residents about the care they are receiving” and “Use humour when talking to residents”)
- IC-COMMUNICATION-SS (staff-to-staff): the eleven-item scale asks carers to rate how often (1=never to 4=always) over the past seven days they have used certain forms of communication with their colleagues (e.g. “Offer ideas for

making changes within the care plans of residents”, “Ask other staff what I should know before caring for a particular resident”).

The IC was originally developed to measure individualised care provided in long-term care facilities for people with dementia. Examination of the factor structure of each scale found that shorter versions of the scales could be adopted (Chappell et al., 2007), however the authors suggested using the longer versions as they cover each domain more comprehensively. The scales have demonstrated acceptable reliability properties in terms of internal consistency (alpha ranging 0.64-0.80) and test-re-test reliability (Pearson's r ranging 0.56-0.88), although the authors have argued that they would benefit from further testing in different samples and further research to assess their validity is warranted.

Tool for Understanding Residents' Needs as Individual Persons (TURNIP) (Edvardsson et al., 2011). The TURNIP is a 39 item tool which was designed as an evidence base for interventions aimed at improving staff's abilities to provide care in a person-centred manner for people in aged care. It contains items pertaining to five dimensions of care which include Environment, Attitudes, Knowledge, Organisation and Care. Items are rated on a 4-point Likert scale ranging from 1 (Strongly Disagree) to 4 (Strongly agree) and example items include: 'Residents are involved in care decisions when they can'; 'There is a pleasant atmosphere'. In the present study, the wording of items referring to persons with dementia were adapted to refer to people with ID, and for example items such as 'People with dementia have hope' were changed to 'People with learning disabilities have hope'. Although the authors have argued that this tool was not intended for use as an evaluative research tool aimed at measuring the level of person-centred care provided by staff, this questionnaire can provide a comprehensive picture of the environment in which people are living and of the care received. The authors argued that an appropriate research tool can be derived from thirteen items contained in the TURNIP which together form what has been called the Person-Centred Assessment Tool (P-CAT), a self-report assessment scale which measures the extent

to which staff working in long term care facilities rate the work settings to be person-centred. The scale has been found to be valid and reliable for use in hospitals and residential settings. The scale covers broad areas of person-centeredness, organisational support and environmental accessibility (De Silva, 2014).

Since no measure to assess person-centred approaches to care specifically designed to be used in relation to people with ID was found and since the study is exploratory it was considered appropriate to be more comprehensive rather than restrictive and therefore adopt the TURNIP rather than the shorter P-CAT. Nevertheless items in the P-CAT are contained in the TURNIP and it is therefore possible to conduct separate analysis using the P-CAT only.

Resident Choice Assessment Scale (RCAS; Kearney et al., 1995a). The RCAS is a 25-item measure of choice availability in residential settings for people with ID. Items are completed by staff and are rated on a 7 point Likert scale which ranges from 1 (never) to 7 (always) with higher scores indicating higher choice availability. Items relate to choices surrounding everyday events such as meals and activities and example items include “How often does the client choose his own clothes in the morning?” and “Does the client have a choice at mealtime (e.g., ham vs. steak)?”. Carers completing the measure are instructed that it is a measure to assess levels of available choice in an individual’s living environment and not his/her capacity, or lack thereof, to make choices. The RCAS has demonstrated significant test-retest reliability (0.91), inter-rater reliability (0.84), and favourable construct validity, as it has been shown to be able to discriminate between large, more restrictive (e.g., developmental centres and nursing homes) and smaller, less restrictive living environments (e.g. group homes) with significantly lower scores in the former settings (Kearney, Cook, Chapman, & Bensaheb, 2006; Kearney et al., 1995a). A previous examination of its factor structure in a sample of participants living in a developmental centre (100 beds), three nursing homes (99–270 beds), and intermediate care/foster facilities with six or fewer beds (see Kearney, Bergan and McKnight (1998) for sample details) produced mixed

findings: principal components analysis (PCA) of the RCAS was suggestive of one and two-factor solutions, but confirmatory factor analysis did not support a two-factor model. The supported solution was given by a five-item single factor model which, was suggested, could be used as a short choice measure (Kearney et al., 2006). In the present study, the full version of the scale was administered but two of the original items were deleted and substituted with one that would combine both. The two original items were “Does the client choose his/her own activities at day treatment” and “Does the client choose his/her own recreational activities?”; the new item which replaced them was “Does the client choose his/her own activities during the day?” This decision was made because the questionnaires were administered to paid carers working in the homes of people with ID, who would not necessarily be aware of the support received outside the home on behalf of other agencies, and thus may have not been able provide accurate answers for questions regarding such activities. The new item asked about activities in general during the day, to distinguish it from another item pertaining to activities in the evening.

Although in the last few decades a number of instruments to measure choice availability for people with ID in different living environments have been developed, this particular measure was chosen as it can be self-completed by direct-care staff, which was considered more appropriate in the context of this study than a measure that would require administration via interview (Hatton et al., 2004; Stancliffe & Parmenter, 1999).

Face Validity

Before administering the questionnaires to paid carers for the purpose of data collection they were firstly presented to the PhD supervisors who are experts in the field of ID research and to a small group of paid carers to establish face validity. A smaller random selection of items from the questionnaires were also discussed with members of Camden SURGE at The Advocacy Project, a group of people with ID who

have been actively involved in providing advice on the larger PBS study and its related activities. Overall individual items were reported to have face validity.

Procedure

Paid carers were asked to complete the questionnaires which were typically left with them to complete in their own time after a PBS study assessment or sent in the post. In order to control for order effects, questionnaires were presented in a different order which was randomly generated in Excel each time (see Appendix B2 for an example of a questionnaire pack including the participant information sheet and consent form). Participants who returned the questionnaire were thanked for their participation and given a £10 voucher.

Statistical Analysis

IBM Statistics SPSS 22 with the R-Menu v 2.0 was used to run the data analysis. For all measures the following steps were undertaken during the analysis:

- Item-analysis. Items with 50% or more missing values were inspected and if not considered critical for the analysis they were removed (Tabachnick & Fidell, 2001); non-discriminatory items (those for which 90% or more of respondents answered the same) were also removed (Chappell et al., 2007).
- Reverse-phrase items were reversed-scored in line with the rest of the scale.
- Missing item-level values, which were limited, were imputed with the Expected-Maximisation (EM) algorithm.
- Factorability for each scale was assessed with both the Kaiser-Meyer-Olkin Index (KMO) test and Bartlett's test of sphericity. It has been suggested that a KMO index value should be at least 0.60, which is considered mediocre, and better results are achieved with higher values (Field, 2005); Bartlett's test of sphericity should have a *p* value smaller than 0.05. The diagonals of the anti-correlation matrices were also inspected for any values smaller than 0.5.

- Following the procedure described by Courtney (2013) Minimum Average Partial (MAP)(Zwick & Velicer, 1986) and Parallel Analysis (PA)(Horn, 1965) were used to determine *a priori* the optimal number of factors to retain (Kearney et al., 2006). Although the most popular methods for retention of factors are Kaiser's 'eigenvalue greater than 1' criterion and visual inspection of the scree plot, it has been argued that both these methods lead to inaccurate conclusions about the number of factors to retain. Kaiser's criterion has been often criticised for over-extracting factors (Beavers et al., 2013; Costello & Osborne, 2005) and the scree plot, which is a graphical representation of the factors, can be quite subjective and open to interpretability, particularly when there may be more than one "bend" or where it is unclear where the cut-off point occurs. MAP and PA are thought to yield optimal solutions even though they are less widely adopted in the literature, due to unavailability in standard software packages (Courtney, 2013; Henson & Roberts, 2006) .
- Dimension reduction analyses (PCA or Exploratory Factor Analysis (EFA)) were conducted and factor structures explored. Details of the analyses conducted for each scale are presented separately. Only items with factor loadings greater than 0.4 and communalities greater than the suggested cut-off point of 0.2 (Gie Yong & Pearce, 2013) were considered for inclusion in each factor.
- Internal consistency for each factor was determined by calculating Chronbach's alpha. Chronbach's alpha was also calculated for each measure's total score.
- Construct validity of the RCAS was explored by assessing whether the measure would show significant differences across types of accommodation and level of ID of the person supported by the carer completing the questionnaire. Previous research has consistently shown that choice availability is typically higher for those living in smaller home-like facilities compared to larger congregate settings (Emerson, et al., 2001; Kearney et al., 2006; Stancliffe, 2001; Stancliffe & Parmenter, 1999) and for those with less severe intellectual disability and higher

adaptive behaviour (Hatton et al., 2004; Lakin et al., 2008; Robertson et al., 2001; Ticha et al., 2012). There is however no consistent research indicating whether person-centred practices differ significantly across different types of accommodation within the community. Previous research has shown that typically community settings are associated with better outcomes for people with ID (Felce & Perry, 1995b; Heller, 2002; Heller et al., 1998) in comparison to more institutional settings, however within community settings it is unclear whether there is great variation between the different types of accommodation (i.e. supported living vs. residential care) in the quality of care provided. In terms of level of ID evidence suggests that individuals with higher abilities typically receive more attention, contact and assistance from staff (Beadle-Brown et al., 2016; Jones et al., 1999) and this could suggest that other person-centred variables such as knowing the individual, communication and autonomy promotion may be enhanced for those with less intellectual impairment. Nevertheless the point of assessing construct validity is to test the measures' ability to differentiate between groups *known* to differ with respect to the construct that they claim to measure and therefore where there is no solid evidence of such differences, testing those differences is obsolete. Construct validity was therefore only tested for the RCAS (the IC and TURNIP's differences across level of ID and residential settings have been reported in the next chapter).

Shapiro-Wilk's test of normality and Levene's test of homogeneity of variance were conducted in order to assess the suitability of parametric statistical analyses (ANOVA) to explore differences between the groups. Where the assumption of normality was not met the non-parametric Kruskal-Wallis H test was performed to explore differences between groups with equal variances. Where in addition to the assumption of normality, the assumption of homogeneity of variance was also violated an ANOVA with Welch's correction was applied. The test has been shown to be robust when variances between groups are unequal and it is accurate even

with non-normal data when there are at least 15 cases per group if there are 2-9 groups (Frost, 2014). Post-hoc pairwise comparisons with Bonferroni corrections were performed to elucidate any significant differences across the groups.

- Due to the absence of other measures of person-centred support or choice in the present study, convergent validity (sub-type of construct validity which measures the degree to which to constructs which should be related are in fact related) was assessed by conducting bivariate correlations between the resulting scales using Spearman’s rho correlation coefficient.

Results

109 paid carers (82% response rate) from 66 different care providers completed the questionnaires. The paid carers’ demographics are presented in Table 3.1. There was no significant difference in terms of gender, education, number of years experience working with people with ID and length of acquaintance with service-users between carers who responded to the questionnaires and those who didn’t. Non-respondent carers’ demographics are presented in Appendix B3.

The service-users in the care of the respondents were individuals with mild to severe ID and challenging behaviour. Service-users’ characteristics are presented in Table 3.2.

Table 3.1. Paid Carers' demographics

Age (Mean, SD)	43.32 (13.05)
Males N (%)	37 (33.9)
Education N (%)	
Degree/Higher Education	34 (31.2)
O/A-levels*	47 (43.1)
GCSE**	17 (15.6)
Other/Missing	11 (10.1)
Years experience working with people with ID (Mean, SD)	10.76 (7.6)
Years acquaintance with service-user (Mean, ID)	5.17 (4.7)

*Ordinary/Advanced level of the General Certificate of Education awarded in England, Wales and Northern Ireland, typically required for admissions to college/university

**General Certificate of Secondary Education (an examination set especially for secondary-school pupils of about age 16 in England, Wales, and Northern Ireland).

Table 3.2. Service-users' demographics

Age (Mean, SD)	43.9 (14.4)
Adaptive Behaviour (SABS)* (Mean, SD)	52.33(23.56)
Challenging Behaviour (ABC) (Mean, SD)	51.01 (27.04)
Males N(%)	73 (67)
Intellectual impairment N(%)	
Mild	12 (11.0)
Moderate	47 (43.1)
Severe	50 (45.9)
Autism Spectrum Disorder (informant reported) N(%)	53 (48.6)
Autism N(%)**	18 (16.7%)
Physical Health Problems	
No	28 (25.7)
Yes:	75 (68.8)
Mobility	17 (15.6)
Sensory	19 (17.4)
Epilepsy	30 (27.5)
Incontinence	29 (26.6)
Other	40 (36.7)
Residential Setting N(%)	
Residential Care Home	61 (56)
Group Supported Living (24-hours)	25 (22.9)
Individual Supported Living (24-hours)	23 (21.1)

*Short Adaptive Behaviour Scale (Hatton et al., 2001)

** Assessed with the mini version of the Psychopathology Assessment Scale for Adults with Developmental Disability (mini PASADD) (Prosser et al., 1998).

Adaptation of the measure of Individualised Care

Item Analysis

Non-discriminatory items were present in two of the subscales (IC-Know and IC-Communication) and were dropped from further analyses. These items with their respective endorsement percentages are presented in Table 3.3. None of the variables had 50% or more missing data and therefore all were retained. There were a total of 10 missing values out of a possible 4469 (0.2%). These were imputed with the EM algorithm which has been considered a suitable method (superior than mean imputation) when the total of missing data is smaller than 5% (Tabachnick & Fidell, 2001).

Table 3.3. Non-discriminating items with percentage of respondents for each response interval

Question	1	2	3	4
IC-KNOW				
I have a good understanding of the resident I am caring for	0	0	9.2	90.8
Favourite beverages, meals and activities are part of a resident's day	0	1	13	95
IC-COMMUNICATION				
Exchange information about residents at shift change	0	0.9	7.3	91.7

Factor Analysis

In their analyses Chappell et al. (2007) used PCA to determine the measures' components structure. Although it has been argued that Exploratory Factor Analysis (EFA) is a superior analytic technique which is usually preferable over PCA (Osborne, 2014), it has also been proposed that PCA may be more appropriate when researchers are just exploring the relationships between variables without previous theory, to see what patterns emerge in the data in their sample (Brown, 2009). Since this was the first assessment of the IC in a sample of people with ID this approach was considered more appropriate and furthermore it allowed for comparisons with the results obtained by Chappell et al. (2007) in a sample of older people with dementia where the same analytic technique was used. A further advantage of PCA is that it does not require variables to be normally distributed. This approach was used for all IC scales. The original authors (Chappell et al., 2007) considered each IC scale separately and for consistency the same approach was adopted in the present study.

IC-Know

The Kaiser–Meyer–Olkin Index of sampling adequacy value (KMO = 0.613) verified the sampling adequacy for the proposed analysis, albeit the value being mediocre (Field, 2005); Bartlett's test of sphericity was significant (approximate Chi-square = 115.601; $p < .001$) and the diagonals in the anti-image matrix were all above .50 therefore indicating that the analysis with eleven items was suitable.

MAP and PA components retention analysis suggested that one component should be retained and therefore a PCA with the number of components fixed to one was conducted. The results showed that all items but three loaded on to the component which explained 21% of the variance; their communalities also had values above the 0.2 cut-off point. Table 3.4 shows the component matrix for this solution with respective communalities. Numbers in bold represent loadings greater than 0.4.

Table 3.4. IC-Know rotated component matrix and communalities.

Item	Loading	Communality
7. I know what the residents I care for like	.621	.386
13. I do not feel like I know each resident as a unique individual	.576	.332
11. I am aware of the skills that residents have and include them into my care approaches	.537	.288
6. I do not know the individual patterns of individual residents	.507	.257
9. I do not think the care plans are based upon what the individuals value in life	.497	.247
1. I read the social histories of resident care plans	.454	.206
8. I find it hard to talk to the residents because I do not know much about them	.448	.201
2. I do not have the time I need to read the social histories of the residents	.405	.164
10. I plan a residents' personal care routine using the habits and routine they had at home	.301	.091
4. I talk to family members and friends in order to learn what has been and may remain important to the resident	.284	.081
3. The quality of the resident social histories is poor	.239	.057

IC-Autonomy

KMO (.806) and Bartlett's sphericity test (approximate Chi-square = 550.916; $p < .001$) values were acceptable to proceed with the analysis. Both MAP and PA indicated that two components should be retained and therefore a PCA with an oblique rotation was performed. Examination of the component correlation matrix showed that the correlation coefficients were smaller than the recommended value of 0.32 (Brown, 2009) and therefore the analysis was repeated with an orthogonal varimax rotation which resulted in a clear pattern structure which is presented in Table 3.5. The first component which was named *IC-Autonomy*, was formed by eight items with primary loadings ranging from .525 to .802 and it explained 29.01% of the variance; the second component named *IC-Positive Feelings*¹ included five items with primary loadings ranging from .526 to .797 and it explained 18.57% of the variance. Item 11 "I Feel that it is important that residents get to meals on time" did not load onto any factor and therefore was excluded from the final solution.

¹ The items in this component are negatively worded, however since the items were reversed scored higher levels indicate more positive feelings and therefore the component was named positive feelings.

Table 3.5. IC-Autonomy rotated component matrix and communalities

Item	Component 1	Component 2	Communality
	<i>Autonomy</i>	<i>Positive Feelings</i>	
8. Feel the facility you work in offers choice in activity programming	.802	.154	.667
4. Feel the facility you work in supports the independence of residents	.773	-.003	.597
12. Feel that the facility you work in makes an effort to include personal preferences into mealtimes	.738	.095	.554
13. Feel good about the quality of care that you are able to provide at this facility	.734	.296	.627
7. Feel that residents have enough to do during the day	.701	.154	.516
14. Feel that there are enough resources available to you to provide care	.620	.399	.544
6. Feel that you are able to allow residents that you look after to make decisions for themselves	.603	.081	.370
10. Feel that you have enough time to allow residents to do things for themselves	.525	.417	.450
11. Feel that it is important that residents get to meals on time	-.360	.057	.133
2. Feel rushed because of facility routines	.160	.797	.661
3. Feel rushed because of the expectations of other caregivers you work with	.250	.719	.580
5. Feel that the other caregivers you work with have different ideas about how care should be provided	.057	.602	.366
1. Feel like you are not doing all you should in order to care for the residents that you look after	.019	.568	.323
9. Feel that you have done things for residents when they could have done it for themselves	.022	.526	.277

IC-Communication-SR

Although Bartlett's test of sphericity was significant (approximate Chi-square = 56.53, $df = 15$; $p < .001$), the KMO index (0.48) indicated that factorability for this scale was

poor suggesting that it would be inappropriate to conduct a factor analysis in the present sample. Since it has been argued that the KMO index is preferable to Bartlett's test of sphericity to assess factorability (Field, 2006), the decision to not conduct any factor analysis for this scale was based on the KMO value. The measure was therefore left unchanged from its original form in Chappell et al., (2007)

IC-Communication-SS

Since the KMO (0.80) value was good and the sphericity test was significant (approximate Chi-square = 430.49; $df=45$; $p<.001$), factor retention analyses were conducted. Both MAP and PA indicated a one component solution. The component resulting from the PCA included nine items with loadings ranging from .492 to .826 and it explained 42.96% of the variance. One item "Supervisors consider the preferences of staff members when making decisions about residents care" did not load on the component. Table 3.6 shows the loadings and communality values with values in bold representing loading items.

Table 3.6. IC-communication-SS rotated component matrix and communalities

Item	Component	Communality
5. Share care approaches that can help manage the difficult behaviours of residents	.826	.682
6. Talk with other staff members in order to find out the meaning behind difficult 6resident behaviour	.805	.648
8. Offer ideas for making changes within the care plans of residents	.740	.548
7. Tell my supervisors about the need to change a procedure or practice that is no longer working for residents	.731	.534
4. Share approaches that can help residents to do things for themselves	.729	.532
3.. Ask other staff what I should know before caring for a particular resident	.645	.416
2. Staff members tell me about physical changes in residents	.625	.390
1. Share personal information that I learn about residents that may help other staff	.540	.292
9. Play a part in the making of facility procedure and practices	.492	.242
11. Supervisors consider the preferences of staff members when making decisions about residents care	.112	0.12

Internal Consistency

The internal consistency of each component was examined using Chronbach's alpha and respective values are reported in table 3.7. Chronbach's alpha was also calculated

for the IC Total which was obtained by adding the scores from the resulting measures of the PCAs.

Table 3.7. Chronbach's alpha values for IC components

Component	Chronbach's alpha
IC-Know	0.561
IC- Autonomy	0.862
IC-Positive Feelings	0.534
IC-Communication-SR	0.365
IC-Communication-SS	0.841
IC Total	0.842

Correlations between IC domains

Bivariate correlations between all the IC measures are reported in Table 3.8. The table shows that there were significant correlations between the IC-Know, IC-Autonomy and IC-Positive Feelings domains. These results indicate that carers who score higher on knowing the care-recipients also score higher on providing care that reflects greater autonomy and experience more positive feelings (items on this measure were reversed-scored therefore higher scores reflect higher positive feelings).

The staff-to-staff and staff-to-resident communication domains were significantly correlated to each other indicating that carers frequently communicating with their colleagues about the residents they care for are also more likely to communicate with the residents in their care.

The results also indicated that, while communicating often with colleagues was associated with experiencing more positive feelings and promoting greater autonomy in residents, communication with the residents was only significantly associated with more positive feelings.

Finally, no significant association was found between the communication domains and knowing the residents, indicating that greater communication with other colleagues and the residents is not necessarily related to how well paid carers get to know the people they support.

Table 3.8. IC measures' correlation matrix

	IC-Know	IC-Autonomy	IC-Positive Feelings	IC-Communication-SR	IC-Communication-SS
IC-Know	1				
IC-Autonomy	.383*	1			
IC-Positive Feelings	.435**	.497**	1		
IC-Communication-SR	.164	.032	.234*	1	
IC-Communication-SS	.181	.360**	.293**	.326**	1

*Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

Adaptation of the Tool for Understanding Residents' Needs as Individual Persons

Item Analysis

Of the 39 original items two were removed as more than 90% of participants gave the same answer on the questions. The removed items were “It is important to know the life histories of people with learning disabilities” and “Social participation is important for people with learning disabilities” which the great majority of respondents strongly agreed with.

There were twelve (0.29%) missing values in the dataset out of 4033 and these were imputed with the EM algorithm.

Factor Analysis

Given the exploratory nature of the use of the scale in a population with ID as opposed to dementia, and the desire for consistency with analyses conducted by the original authors, dimension reduction analysis was performed using PCA.

The Kaiser–Meyer–Olkin Index of sampling adequacy value (KMO = 0.692), albeit being mediocre, verified the sampling adequacy for the proposed analysis in addition to Bartlett’s test of sphericity which was significant (approximate Chi-square 1556.43; $p < .001$);

MAP and PA analysis suggested that the measure should be reduced to three components and therefore a PCA with an oblique rotation with said number of

components was performed. The results however indicated that there were three items (“It is necessary to hurry residents to accomplish all that needs to be done”, “People with learning disabilities should always be oriented to reality” and “The quality of the interaction between staff and residents is more important than getting stuff done”) with diagonals of the anti-image correlation matrix smaller than 0.5 and therefore the analysis was repeated by omitting them. The results of this analysis however also conveyed two items (“People with learning disabilities have ways of communicating what they want or don’t want” and “People with learning disabilities are as different from each other as any other group of people who share a disease category”) with diagonal values smaller than 0.5 which were in turn removed. A further analysis with an oblique rotation suggested that the components may not actually be correlated as all correlation coefficients between them were smaller than 0.32. A PCA with a varimax rotation was thus performed. The sampling adequacy was improved (KMO = .737); two items did not load onto any factor and were therefore deleted. The rotated component matrix for the retained solution with components loadings and respective communalities is presented in Table 3.9. The first component labelled *Environment and care* included seventeen items and explained 19.68% of the variance; the second component (*Organisation*) included seven items and explained 10.96% of the variance; the final component (*Attitudes and knowledge*) had six items and it explained 8.9% of the variance.

Table 3.9. TURNIP rotated component matrix and communalities²

Variable	Component			Communality
	<i>Environment and care</i>	<i>Organisation</i>	<i>Attitudes and knowledge</i>	
The environment supports personal choice	.700	.408	-.108	.669
There is a homely feel to the place	.685	.042	-.045	.472
We often discuss how to give person-centred care (between staff)	.673	.034	.039	.456
There is a pleasant atmosphere	.661	.262	-.064	.510
Residents have a variety of foods to choose from	.612	.146	-.035	.397
The environment supports residents to express their personal identity	.607	.287	-.116	.465
Residents are offered the opportunity to be involved in individualised everyday activities	.593	.156	-.091	.384
People with learning disabilities have meaningful relationships	.590	-.193	.225	.436
I would like to live here if I had a learning disability	.540	.382	-.175	.469
It is hard for residents at this facility/home to find their way around	.519	-.120	.042	.285
We have formals team meetings to discuss residents care	.518	.323	.045	.375
Assessment of residents' needs is undertaken on a daily basis	.503	.152	.120	.291
Residents are involved in care decisions when they can	.492	.238	.081	.306
Residents are able to access outside space as they wish	.483	.053	-.148	.258
In my workplace residents are given the opportunity to perform tasks according to their abilities	.480	.350	-.196	.391
The life histories of residents is used in the care plans we use	.442	.189	-.204	.273
We are free to alter work routines based on residents' preferences	.437	-.088	.017	.199
This organisation prevents me from providing person-centre care	.095	.769	.127	.616
The environment feels chaotic	.209	.598	-.231	.454
Labels (e.g. wanderer, screamer) are	-.126	.595	.201	.411

² The different colours reflect the components of the original measure: blue=environment, orange=organisation, pink=care, green=attitudes, purple=knowledge

Variable	Component			Communality
	<i>Environment and care</i>	<i>Organisation</i>	<i>Attitudes and knowledge</i>	
<i>used to describe individuals</i>				
I simply do not have the time to provide person-centred care	.126	.581	.189	.389
I feel supported by the organisation I work in	.372	.522	-.028	.412
We have to get the work done before we can worry about a homelike environment	-.037	.432	.418	.363
Residents can choose between interacting with others and being alone	.164	.426	-.016	.208
In learning disabilities the body is there but the person is gone	-.064	.034	.726	.532
Challenging behaviours are inevitable in people with learning disabilities	.051	-.042	.680	.466
People with LD should be allowed to form sexual relationships	.042	-.029	.617	.383
Learning disabilities reduce the experience of pain	-.082	.242	.566	.385
There is often no alternative to using restraints	-.168	.107	.475	.265
People with ID have hopes	.380	-.135	.435	.351

Internal consistency

Internal consistency was measured for each component: Chronbach's alpha for the *Environment and care* component was .867; it was .703 for *Organisation* and .658 for *Attitudes and knowledge*. Chronbach's alpha for the scale's total score was .831.

Bivariate correlations between TURNIP domains

The results of the correlations which are reported in Table 3.12 (p.109) indicated that there was a significant correlation between *Environment and care* and *Organisation*. The *Attitudes and knowledge* domain on the other hand was not significantly correlated with either domain.

Update of the Resident Choice Assessment Scale

Item analysis

None of the items had more than 90% of people respond in the same manner and therefore all were retained.

Deletion of variables with more than 50% missing data

The variable “Does the client choose his/her roommate?” was left blank by 63% of respondents. None of the residents in the present sample shared a room with anyone else and it is typical nowadays for people with ID who live in shared supported housing or in residential care homes in the community to have their own bedroom. The variable was therefore not considered appropriate for the analysis and it was thus removed from the dataset.

Missing items

After removing the previously mentioned variable there were 45 missing values out of a total of 2484 possible responses (1.81%). Forty of those values were from one variable (“Does the client choose which type of adaptive equipment or prosthetic device to use?”) which was left blank by 37% of respondents

Factor Analysis

The Kaiser–Meyer–Olkin Index of sampling adequacy value ($KMO = 0.851$) verified the sampling adequacy for the proposed analysis (Field, 2005); Bartlett’s test of sphericity was significant (approximate Chi-square = 1514.45; $p < .001$) and the diagonals in the anti-image matrix were all above .50 suggesting reasonable factorability. Since the scale had already been validated and its factor structure previously examined in this population group (Kearney et al., 2006), it was considered more appropriate to use EFA which is analytically superior (Osborne, 2014).

The results of both MAP and PA suggested that two factors should be retained. This is consistent with the solution that was chosen in a previous analysis where factor

retention had been guided by the Kaiser's eigenvalue criterion and inspection of the scree plot (Ratti, Vickerstaff, Crabtree, & Hassiotis, 2017).

Principal Axis Factoring (PAF; does not assume normally distributed variables) with an oblique rotation (Direct oblimin) forcing a 2 factor structure solution was thus conducted. The first factor (labelled *Everyday choices*) had an eigenvalue of 9.293 and it explained 31% of the variance. Thirteen items loaded on to it with loadings ranging from 0.54 to 0.94. Factor 2 had an Eigenvalue of 2.052 and it explained 14% of the variance. The factor was labelled *Participation in household activities* and it had five items with factor loadings ranging from 0.45 to 0.76. The two factors cumulatively explained 45% of the variance and their correlation coefficient was 0.46. Four items ('Is the client's door locked at night?', 'May the client take walks outside by him/herself?', 'Is the client allowed to be in his/her room alone during the evening?' and 'Is the client allowed to move around the home/building as he/she wishes?') had communalities below the 0.2 cut-off point and they did not load onto any factor. An additional item 'Does the client choose whether he/she receives therapy sessions?' did not load onto any factor although its communality was greater than 0.2. Table 3.10 shows the factor pattern matrix for this solution with respective communalities. Bootstrapped confidence intervals for each factor loadings are presented. Numbers in bold represent primary factor loadings.

Table 3.10. RCAS factor loading pattern matrix and communalities

Item	Factor 1 <i>Everyday Choices</i>	Bootstrapped CI	Factor 2 <i>Participation in household activities</i>	Bootstrapped CI	Communality
Does the client choose the time he/she brushes his/her teeth?	0.94	0.58-1.24	-0.15	-0.59-0.47	0.77
Does the client choose the time he/she takes a bath/shower?	0.89	0.57-1.15	-0.12	-0.53-0.41	0.69
Does the client choose the time he/she wakes up in the morning?	0.74	0.46-0.96	-0.23	-0.62-0.26	0.44
Does the client choose his/her bedtime?	0.68	0.42-0.91	0.00	-0.32-0.43	0.46
Does the client choose his/her own activities during the day?	0.68	0.24-1.16	0.21	-0.23-0.87	0.63
Does the client choose his/her own clothes in the morning?	0.66	0.24-1.12	0.20	-0.18-0.76	0.59
For group activities, does the client chose whether or not he/she participates?	0.63	0.41-0.88	0.05	-0.27-0.43	0.42
Does the client have a choice as to whether he/she has visitors?	0.62	0.30-0.93	0.00	-0.39-0.55	0.38
Does the client choose what activities he/she will participate in during the weekend?	0.61	0.20-1.11	0.32	-0.05-0.87	0.65
Does the client choose which tv program he/she would like to watch?	0.58	0.12-1.07	0.28	-0.16-0.98	0.56
Does the client have a choice at mealtimes (e.g. ham vs. steak)?	0.58	0.21-1.02	0.25	-0.12-0.74	0.53
Does the client have a choice as to when he/she eats (e.g. 6.00 or 6.30)?	0.57	0.11-1.03	0.14	-0.31-0.80	0.41

Item	Factor 1 <i>Everyday Choices</i>	Bootstrapped CI	Factor 2 <i>Participation in household activities</i>	Bootstrapped CI	Communality
Does the client have a choice what radio program he/she would like to listen to?	0.54	0.09-1.05	0.37	-0.05-0.37	0.61
Is the client allowed to be in his/her room alone during the evening?	0.39	0.14-0.60	-0.13	-0.40-0.16	0.12
Is the client allowed to move around the building/home as he/she wishes?	0.32	0.03-0.64	0.17	-0.13-0.51	0.18
May the client take walks outside by him/herself?	0.28	0.05-0.54	0.08	-0.24-0.48	0.10
Does the client participate in the clean up after meals?	-0.02	-0.39-0.54	0.76	0.53-1.07	0.56
Does the client participate in doing his/her laundry?	-0.02	-0.38-0.54	0.74	0.40-1.07	0.54
Is the client responsible for all or part of the clean-up of his/her bedroom?	0.06	-0.27-0.61	0.68	0.35-1.01	0.51
Does the client choose which type of style or prosthetic device he/she utilises (e.g. wheelchair, braces)?	0.34	-0.02-0.79	0.45	0.05-0.96	0.45
Does the client participate in the preparation of meals?	0.06	-0.18-0.42	0.45	0.15-0.95	0.23
Does the client choose whether he/she will receive therapy sessions (e.g. speech, language, occupational, music)?	0.39	0.06-0.82	0.38	0.00-0.82	0.42
Is the client's bedroom door locked at night?	0.09	-0.09-0.26	0.10	-0.15-0.44	0.02

A further EFA with the same methodology which omitted the non-loading items resulted in the same factor structure. The factors cumulatively explained 53% of the variance (the factor pattern matrix is reported in Appendix B4)

Construct validity

Construct validity was assessed by investigating whether the factors would identify different levels of choice availability and participation in household activities across different living environments and across people with different levels of intellectual impairment. The results are presented in the following sections.

Shapiro Wilk's test of normality showed that both factors were non-normally distributed and thus not suitable for parametric analyses (see Appendix B5).

1. Residential settings.

Levene's test of homogeneity of variance revealed that there were no significant differences between the variances of each factor in the different accommodation types (see Appendix B5 for all homogeneity of variance tests). The Kruskal-Wallis H test indicated that for both Factor 1 ($H(2)=8.04, p=.018$) and Factor 2 ($H(2)=11.89, p=.003$) there were significant differences across the different accommodation types; these differences were subsequently explored via pairwise comparisons. The Bonferroni adjustment was used to counteract the problem of multiple comparisons (three for each factor) and the significance level was therefore set at $p=.016$. Mann-Whitney U tests revealed that scores on both factors were significantly different for people living in group supported living compared to those living in residential care homes, with carers providing the most choice and participation in household activities in group supported living and the least in residential care homes (Factor 1: $U=486.00, p=.008$; Factor 2: $U=474.50, p=.001$). The difference between participation in household activities in residential care compared to individual supported living was approaching significance ($U=454.00, p=.025$). None of the other comparisons were statistically significant. The

factors' mean scores are presented in Table 3.11, with higher scores indicating greater choice and participation in activities.

Table 3.11. Factor 1 and Factor 2 mean scores across residential settings and level of ID

	Factor 1 Mean (SD)	Factor 2 Mean (SD)
Residential Setting		
Supported Living - Individual	80.45 (12.97)	25.94 (6.55)
Supported Living – Group	81.94 (13.85)	27.93 (7.04)
Residential Care Home	74.01 (17.03)	22.39 (7.72)
Intellectual disability		
Mild	83.96 (8.13)	27.91 (7.01)
Moderate	81.65 (11.27)	26.65 (6.90)
Severe	71.40 (18.82)	22.03 (7.73)

2. Level of ID of care-recipients.

A Homogeneity of variance test indicated that the group variances for Factor 1 across the different levels of ID were significantly different and therefore differences between the groups were tested with a One Way ANOVA with Welch's correction. The test revealed a significant difference between the groups ($F(2,39.86)=7.01$, $p=.002$) and Games-Howell post-hoc tests indicated that choice availability scores for people with severe ID were significantly lower compared to those with mild ($p=.003$) and moderate disability ($p=.005$). Scores for people with mild and moderate ID were comparable.

For Factor 2 Levene's test was not significant, indicating equal variances between groups. Since however the assumption of normality was violated, for consistency with previous analyses the non-parametric Kruskal-Wallis H test was adopted to compare differences between different levels of ID. The test was significant ($H(2)=11.29$, $p=.004$) and pairwise comparisons indicated that there were significant differences in scores between those with severe ID compared to those with moderate ($U=740.00$, $p=.003$) and mild ID ($U= 64.50$, $p=.016$). The mean scores per level of intellectual impairment for both factors are presented in Table 3.11.

Internal Consistency

Cronbach's alpha for Factor 1 'Everyday Choices' and Factor 2 'Participation in household activities' were 0.933 and 0.843 respectively. Chronbach's alpha for the total score was 0.917.

Convergent validity

Bivariate correlations using Spearman's rho (non-normally distributed data) were conducted between all components/factors which emerged from the previous analyses and the results are presented in Table 3.12.

Correlations were also performed between the total scores of each measure which were obtained by adding the scores for each of the measures' components/factors. As can be seen in Table 3.13 there were significant correlations between all of the measures' total scores.

Table 3.12. All measures correlation matrix

	IC Know	IC Autonomy	IC- Positive Feelings	IC- Communication- SR	IC- Communication- SS	Environment and care	Organisation	Attitudes and knowledge	Everyday choices	Participation in household activities
IC-Know	1									
IC-Autonomy	.383**	1								
IC-Positive Feelings	.435**	.497**	1							
IC- Communication- SR	.164	.032	.234*	1						
IC- Communication- SS	.181	.360**	.293**	.326**	1					
Environment and care	.323**	.556**	.402**	.207*	.458**	1				
Organisation	.426**	.456**	.462**	.097	.299**	.434**	1			
Attitudes and knowledge	.082	.035	-0.98	.137	.035	.075	.145	1		
Everyday choices	.204*	.243*	.108	.081	.252**	.294**	.226*	.085	1	
Participation in household activities	.111	.124	-.031	-.014	.234*	.308**	.047	.212*	.507**	1

* Correlation is significant at the 0.05 level (2-tailed).

**Correlation is significant at the 0.01 level (2-tailed).

Table 3.13. Measures' totals correlation matrix

	IC Total	TURNIP Total	RCAS Total
IC Total	1		
TURNIP Total	.615**	1	
RCAS Total	.279**	.346**	1

*Correlation is significant at the 0.05 level (2-tailed)

**Correlation is significant at the 0.01 level (2-tailed)

Discussion

The present chapter explored the factor structure of three different measures for use in a sample of paid carers of adults with ID living in the community. Two measures (IC and TURNIP) had never been used with carers of people with ID as they had only been used in the field of older people with dementia, therefore it was necessary to adapt them for use in the present sample. The RCAS on the other hand has been used to measure choice availability for people with ID but it was developed three decades ago and thus it was adapted for use in the current context of care which has seen major changes since the first use of the scale. A discussion of each measure is presented separately followed by a concluding discussion of the limitations of the analyses in the current sample and of future use of the measures.

Individualised Care

The present chapter provided factor solutions for use of the IC measure in people with ID and challenging behaviour which slightly differ from the solutions provided by Chappell et al. (2007) in their original use of the scales for older adults with dementia in long-term care facilities.

The original IC comprised four measures two of which were specifically person-centred measures (IC-Know and IC-Autonomy) and two which were communication-oriented measures (IC-Communication-SR and IC-Communication-SS). All measures were subject to PCA by the original authors which found that each scale could be reduced to

much shorter components. Nevertheless the authors recommended using the longer versions of the scales to be more comprehensive and these were subject to PCA in the present study.

In the present sample results from the PCA were suggestive of a one factor structure for the IC-Know which was similar to that of the original scale. Although the PCA demonstrated good validity, internal consistency was poor for this component.

In contrast to the original scale which found a one component solution for the IC-Autonomy, the analysis in the present study indicated a two component solution (IC-Autonomy and IC-Positive feelings); The first of those demonstrated good internal consistency but the latter's internal consistency was poor.

For the IC-Communication-SR the factorability analysis revealed that it was inappropriate to conduct any dimension reduction analysis on this subscale and therefore the measure was kept in its original format. Internal consistency analysis nonetheless returned an unacceptable coefficient, therefore suggesting that use of this measure on its own may be inappropriate.

Finally the IC-Communication-SS in the present sample had one interpretable component which included all the original items except one, differently from the interpretable factor in the original measure which only had five loading items. In the present sample internal consistency for this component was good.

Generally compared to the results of the PCA conducted by Chappell et al. (2007), in the present sample the majority of the individual items loaded onto their respective component, with only a small minority of items not loading on them. Thus instead of having short and long versions of each measure it was decided to simply drop the non-loading items.

Although all components, with exception of the IC-communication-SR for which it was not possible to conduct the analysis, had clear interpretable solutions, the results

showed that internal consistency for IC-Know, IC-Positive Feelings and IC-Communication-SR was poor, indicating low reliability and therefore caution is warranted in their use. Nevertheless it has to be taken into account that internal consistency is significantly affected by the total number of items in a scale and shorter measures often demonstrate low reliability and therefore measures should not be discarded solely on the basis of a low reliability coefficient (Tavakol & Dennick, 2011) . The longer IC-Total measure which consisted of the sum of all the individual IC measures demonstrated good internal consistency.

The correlations between IC scales/domains were comparable to those found in the original study with significant correlations between the IC-Know and IC-Autonomy domains on one hand and the communication domains on the other. The results suggested that carers who got to know the service-users they cared for also supported their autonomy and experienced less negative feelings; additionally carers who communicated more frequently with other staff about the service-user they cared for were also more likely to communicate more frequently with the service-users and promote their autonomy. Counter-intuitively nonetheless, communicating more frequently with staff and service-users was not associated with how well the staff got to know the service-users. It could be argued that the frequency of communication is not sufficient to get to know someone well, and it may be that it is the quality and content of the interactions that leads to gaining a better knowledge of a person. As suggested by Chappell et al. (2007) not all domains of person-centred support are necessarily related to one another in practice and staff may excel in some domains but not in others. The multi-dimensional nature of person-centred support implies that different dimensions may not necessarily be consistently present. The IC measures attempt to capture some of these domains and may be useful for highlighting areas of good support and those which may require improvement.

Tool for Understanding Residents' Needs as Individual Persons

The TURNIP was originally developed for use by staff working in residential care for older people as a tool to be used in interventions aimed at improving person-centred care. The scale consisted of five dimensions considered central to person-centred care: the care environment, staff attitudes, staff knowledge, the organisation of care and content of the care provided.

The results of the present study did not reflect the same factor structure of the original measure. The PCA in the present sample was indicative of a three components solution in which the original components were aggregated. These components were called 'Environment and care', 'Organisation' and 'Attitudes and knowledge' all of which had acceptable internal consistency coefficients. The total score's internal consistency coefficient was also good.

The tool was originally designed as a response to the difficulty in defining and consequently operationalising person-centred support. The aim was to construct a tool which could be used in interventions aiming to improve person-centred support for older age people. The tool covers various dimensions which may highlight different levels of staff performance in these different areas. As with the IC, not all components were correlated to one another. In the present sample the environment and care and the organisation component were correlated but the attitudes and knowledge component was not correlated with these domains. The authors of the TURNIP did not report correlations analysis between the components and therefore the results of the present sample cannot be compared.

Five items from the original measure did not result to be suitable in the present sample and were therefore discarded. The wording of these items may have been irrelevant or inappropriate for this population e.g. "People with learning disabilities should always be oriented to reality" may have not made sense for many carers.

The authors of the TURNIP argued that the tool is better used as an intervention tool for use in clinical practice rather than an evaluative research tool for which a shorter version of the tool (P-CAT) may be more appropriate (Edvardsson et al., 2010). Nevertheless due to the differences in sample and context in which the tool was administered it was considered appropriate to use the more comprehensive version of the tool in the present project. Only further testing on the tool in samples of people with ID will establish whether the longer or shorter version may be more appropriate for use in research studies. The longer version in the present study resulted in a clear and interpretable solution with acceptable reliability, indicating that it may be used as a starting point to measure person-centred support for people with ID. It would however greatly benefit for further testing to verify its validity and reliability.

Resident Choice Assessment Scale

The present study explored the factor structure of a measure of choice availability (RCAS) for adults with ID and challenging behaviour supported by paid carers in community settings. The study provided a solution for the scale which may be more suitable in the current context of care provision than the original scale, which was developed at a time when the process of deinstitutionalization had begun to accelerate but nonetheless saw a different landscape in the provision of care for people with ID than what we have today.

Results from the EFA were suggestive of a two-factor structure. The factors were named 'Everyday choices' and 'Participation in household activities'. The former included items related to the opportunity for the individual to make choices in his/her daily routine, such as what to eat and what to do and the latter included items relative to the individual's participation in domestic activities, such as preparing meals. Although the PAF demonstrated good factorial validity, the confidence intervals for the factor loadings were fairly large, indicating that the results must be interpreted with caution. Furthermore, the factorial structure in the present sample did not reflect the structure found by Kearney et al. (2006), which was represented by one short factor.

The extraction methods in the two studies were, however, different. The authors of the original study reported conducting “principal components factor analysis”, which was guided by factor retention analysis using minimum average partial and parallel analysis. The choice to use EFA as opposed to principal components analysis (PCA) in the present study was determined by the general agreement among researcher that it is a stronger form of analysis and that PCA is not generally considered a factor-analytic technique (Brown, 2009; Osborne, 2014). The fact that the analyses resulted in different solutions is not surprising as the settings in the two studies differed significantly. Whereas in the present study participants were recruited from community settings including individual supported living, in the previous study none of the participants were recruited from supported-living accommodation types, but were all recruited from developmental centres and nursing homes with a high number of beds or smaller intermediate-care facilities providing medically related services. Furthermore, the original study includes a sample from a previous study published in 1998 (Kearney et al., 1998) which not only took place in different care settings but was also conducted nearly two decades ago. During this time much has changed in terms of ideology and practices in the provision of care for people with ID and these points are what constituted the rationale for a new EFA.

The factors which emerged in the present study demonstrated good construct validity and internal consistency. Five items did not load onto any factor. Some of these items which referred to service-users “being allowed” to move around the home/building or be alone in their room may not be relevant in community settings where the great majority of individuals live in environments where the restrictive practices associated with earlier congregate settings are no longer applied; similarly the item “Is the client’s bedroom door locked at night?” implies restriction and control from staff and may not be appropriate for use in the present day. Kearney et al. (2006) suggested that in future studies the item could be rephrased as “Does the client have a choice as to whether his/her bedroom is locked during the day/night?” The other non-loading items

represented choices which may not be applicable to some service-users (e.g., “Does the client choose whether he/she receives therapy sessions?”) and future administrations of the scale could consider providing a not applicable (N/A) option for respondents.

The results of the EFA suggest that the scale could be reduced to 18 items (RCAS-18) when delivered in community settings and future investigators may consider omitting those items. The item “Does the client choose his roommate?” had been left blank by the great majority of the respondents and was thus deleted from the scale. Nowadays, it is typical for people with ID who live in the community to have their own room and therefore the question may be redundant. In future administrations of the scale, investigators may wish to reword the question and ask whether the service-users decide who they share their home with; it should nonetheless be considered that such question may not be appropriate for the current questionnaire which addresses everyday choices that are typically facilitated by direct-care staff, rather than choices about major life events which have more permanent consequences and are usually decided upon by care managers or other authorities.

Notably, one of the items on the “participation in household activities” factor (“Does the client choose which type of style or prosthetic device he/she utilizes e.g., wheelchair, braces?”) is actually related to choice and it is somewhat surprising that it did not load onto that factor. Nevertheless it has to be noted that this item prior to imputation had been left blank by 37% of respondents and perhaps its loading onto Factor 2 as opposed to the ‘Everyday choices’ factor may be a result of imputation of a relatively large portion of missing data. The large proportion of missing data for this item may have been due to the fact that the item may not be applicable to a great number of individuals who may not require additional health aids. Providing an N/A option in future studies may reduce the amount of missing data and thus provide cleaner datasets.

Construct Validity

In line with the original scale (and previous research such as Wehmeyer & Bolding, 1999), both factors of the RCAS were able to discriminate between different accommodation types, and specifically they were able to differentiate between residential care homes and group supported living. Interestingly, however, the scores on everyday choices and participation in household activities in individual supported living did not significantly differ from those in either residential care homes or group supported living. This is somewhat unexpected, as previous research has shown that choice availability may be higher in smaller, more individualised settings (Robertson et al., 2001; Stancliffe, 2001). However, in England the principles of “choice” and “inclusion” for people with ID have been widely promoted by the White Paper *Valuing People* (Department of Health, 2001) and its successor *Valuing People Now* (Department of Health, 2009), and it is therefore possible that the differences in choice availability and participation in different settings in the community will not be as substantial as one may expect to observe between community living environments and the more restrictive institutions. A recent report from The Centre for Social Justice (2016) emphasized that although supported living services are generally believed to provide a greater degree of autonomy and independence, residential care homes can be just as flexible and achieve high levels of personalisation. The significant difference in the present study found between choice availability in residential care homes and group supported living may be an artefact of the different compositions of the groups residing in those types of accommodation.

In the present sample, residential care homes were more likely to accommodate people with more severe needs which made up 57.14% of the people residing in such facilities; on the other hand, supported living arrangements were more likely to accommodate individuals with lower support needs and less severe intellectual impairments, with only 30% of people in group supported living being classified as having a severe ID. The difference in choice availability and participation in activities

observed in those accommodation types might instead be reflective of a difference between people with different levels of impairment. The scores for both everyday choices and participation in household activities were indeed significantly different for people with different levels of ID. Carers supporting people with more severe learning disabilities provided significantly lower scores than those supporting individuals with moderate and mild ID. This finding is consistent with previous research which has consistently shown that individuals with more severe ID are provided with fewer opportunities to make choices in their everyday life compared to their counterparts with mild and moderate ID (Lakin et al., 2008; Ticha et al., 2012). If the difference observed between residential care homes and group supported living is indeed only an artefact of their different compositions, then this would imply that choice availability and participation in activities is comparable across different accommodation types. This is in contrast with previous literature which found that choice is enabled differently in different types of accommodation (Vandergriff & Chubon, 1994; Wehmeyer & Bolding, 1999). Nevertheless, it provides some optimism for the delivery of care for people with ID, as it could provide an indication that care providers across different settings are embracing the principles of choice and engagement in a similar fashion, despite the recent emphasis on supported living arrangements.

On the other hand it has to be noted that the absence of a significant difference between scores in residential care homes and individual supported living may be a consequence of the conservative Bonferroni adjustment. Had this adjustment not been applied the test would have been reported as statistically significant as the p value was lower than .05. Conversely there was no significant difference in choice between individual and group supported living, which would indicate that care practices may be similar in these types of accommodation but differ from those in residential care homes and it may be that there are certain characteristics within supported living environments which render them more conducive to choice-making than residential care homes.

Strengths and Limitations

The present study has provided solutions for two holistic measures of person-centred support and a measure of choice availability which may be used in a sample of adults with ID living in the community.

There are however a number of limitations in the study. The sample size in the present study was relatively small as it has been suggested that a ratio of 10 respondents per variable should be used when conducting factor analyses (Field, 2005). Others have argued that a subjects-to-variables ratio larger than 5 is sufficient (Beavers et al., 2013) however Osborne (2014) has reported high numbers of published studies with subjects-to-variables ratios smaller than 5:1. Although the sample size could have indubitably benefited from being larger, it did have strengths as it was diverse and it included paid carers with varying years of experience working with the population group, different educational backgrounds, working in various accommodation types in different parts of England including urban and rural areas. As recommended by Kearney et al. (2006), the service-users in their care constituted a diverse sample with different levels of ID. Whereas the study by Kearney et al. (2006) only included individuals with severe/profound intellectual disabilities, the present study also included individuals with moderate and mild disabilities. Future research will need to evaluate the adapted measures in larger samples and over time to further investigate their psychometric properties. Confirmatory factor analyses in different and bigger samples should also be conducted.

An important limitation specifically for the holistic measures was that being their first use in a sample with ID, which was not particularly large, the findings must be interpreted with caution and can only be considered as exploratory. For example, it is unclear from the study if the sub-optimal internal consistency of some of the scales was mostly affected by properties inherent to the scale or to the scales' small number of items. Furthermore, the validity of the measures was not assessed, for example, whilst

construct validity was assessed for the choice measure, it was not assessed for the holistic measures due to the lack of previous research establishing the discriminating properties of person-centred support. Re-test and inter-rater reliability were also not assessed for any of the measures, as the carers who took part in the study had already completed a number of assessments in relation to the PBS study and asking them to complete further assessments was felt to constitute too much of a burden. On the other hand however significant correlations were found between the total scores of the measures and particularly between the two holistic measures, indicating that despite covering different aspects of person-centred support there is some evidence suggesting that they are measuring different facets of the same construct.

Another important limitation is given from the fact that responses on each measure were provided by paid carers who had all taken part in the PBS trial (Hassiotis et al., 2014) and the service-users that they were asked to base their responses on, all had challenging behaviour. The results presented in this chapter therefore may not be generalisable, as paid carers who support individuals with ID without the presence of challenging behaviour may provide support in a different manner.

Previous research has reported that carers who support individuals with challenging behaviour experience more stress, burnout and higher turnover levels (Mills & Rose, 2011; Mitchell & Hastings, 2001) all of which can have an adverse effect on the quality of support provided in turn. It is unclear whether choice availability differs significantly between people with and without challenging behaviour (Lakin et al., 2008; Ticha et al., 2012). Although some studies have found more choice to be associated with lower levels of challenging behaviour (Hatton et al., 2004; Stancliffe, 2001), intellectual functioning, which has been shown to be a significant predictor of challenging behaviour, has often not been controlled for, and therefore the observed relationship between choice and challenging behaviour may be the result of an artefact of its relationship with intellectual functioning. The adapted scales should therefore be

administered to different samples, including carers supporting people without clinically significant or no challenging behaviour.

One of the limitations of self-completed questionnaires is that they may provide biased responses. Answers given by carers may be subject to desirability bias and may not reflect reality. An obvious alternative to reduce bias is to ask people with ID directly about their experiences of the support received. This method however has its own limitations as only those with mild/moderate impairment may be able to answer consistently and those with more severe impairment may not be able to respond thus leading to the exclusion of a significant portion of the sample. If proxy respondents are used only for individuals with more severe impairment, it has to be taken into account that the accuracy of the responses may differ across the sample. In response to this issue Hatton et al. (2004) developed a choice measure which, where service-users cannot respond directly for themselves, caregivers are asked to provide concrete examples of how choice is made available and a rating is given by the researcher. This method may be helpful to reduce bias, however administering measures by interview may be time-consuming and not always practical. A major strength of the measures used in this study is that they can be self-completed in short amounts of time.

Conclusion

Although the study can only be considered as exploratory and all of the measures require further testing of their validity and reliability in different samples, the present chapter provided a first step towards research tools in the area of person-centred support for adults with ID supported by paid carers in the community.

The two holistic measures are unlikely to be exhaustive measures of person-centred support as it is such a multi-faceted concept; however in the absence of other non-observational staff-based measure in the field of ID, the measures may provide a starting point to explore this construct in relation to other variables.

With regards to the choice measure the study provided new information regarding the RCAS's factor structure in a different context and examined the construct validity and internal consistency of the emerging factors. The results of the analyses indicate that a scale with two factors may be reduced to a scale with 18 items (RCAS-18) with the potential to be used as an evaluative research tool to objectively assess everyday choices and participation in household activities. As with any other measure of choice, as argued by Stancliffe and Parmenter (1999), the RCAS cannot capture all the possible available choices as the possibilities to make choices are infinite, and therefore absolute content validity is impossible to achieve.

In the next chapter the measures described in this chapter are used in the context of a cross-sectional study investigating the relationship between person-centred support/choice and other variables including challenging behaviour, in the same sample of adults with ID.

Chapter 4. Person-centred support in adults with intellectual disabilities and challenging behaviour supported in the community by paid carers: results from a cross-sectional study

Introduction

In the previous chapter measures of person-centred support previously used in the research field of dementia were subject to factor analysis in order to find solutions that would be more appropriate to use with people with ID living in the community. Additionally a measure of choice which was developed three decades ago was updated for use in the current context of care.

In this chapter the three measures were used in a cross-sectional study investigating person-centred support in adults with ID and challenging behaviour living in the community and supported by paid carers.

Background

As described in Chapter 2 person-centred support has become synonymous with good quality care, despite the difficulty in measuring the construct and its operationalisation. The measures described in the previous chapter constitute a first step to measure the construct in the field of ID and in this chapter person-centred support was explored within the context of home environments in the community for this population group in England, UK between 2015-2016. Person-centred support was explored in association with residence characteristics, community participation and carer variables. The main aim of the research presented in this chapter was however to explore whether person-centred support was associated with challenging behaviour in adults with ID.

Person-centred support in community settings

Since the deinstitutionalisation movement in the 1970s there has been a lot of research focusing on the impact of the living environment on outcomes for people with ID. Heller et al. (1998) argued that the majority of this research has focussed on size and type of accommodation as the primary predictors of outcomes and typically better outcomes such as quality of life, residential satisfaction and self-determination have been found in smaller community settings which differ significantly from the larger institutions.

The great majority of research investigating these predictors, particularly the earlier studies, drew comparisons between institutional and community-based settings but there are fewer studies comparing different accommodation types within the community (Emerson et al., 2001; Stainton, Brown, Crawford, Hole, & Charles, 2011).

Studies comparing community settings have found that living-unit size is indeed associated with better outcomes and particularly relevant to the current project are the findings that smaller community facilities have been associated with greater levels of choice and control (Emerson et al., 2001; Stancliffe, 1997; Tossebro, 1995) and individualised support (Heller, 2002; Heller et al., 1998). Bigby & Beadle-Brown (2016) reported that the best outcomes are achieved in small-scale community settings accommodating between 1 and 6 individuals, however it has also been argued that there is great variation within community services and facility size is just one of many predictors of better outcomes; facilities with fewer residents do not necessarily bring inevitable improvements in the lives of people with ID (Heller, 2002) and the number of people living together may not have as much strong influence on quality of life as commonly considered (Felce, 2017; Kozma, Mansell, & Beadle-Brown, 2009).

It is unclear whether the quality of support differs significantly across different accommodation types in the community. Emerson et al. (2001) found that although there was no difference in person-centred planning between different accommodation

types, there was significantly more staff support to residents in supported living accommodation compared to both small and large group homes.

As has been proposed in the NICE draft guidance *Learning disabilities and behaviour that challenges: service design and delivery* (NICE, 2017), investigating the effect of size and type of residency on outcomes is important to guide commissioners and service providers' housing investment decisions and to ensure that the best housing options are provided for people with different support needs.

In the first section of this cross-sectional study I aimed to explore whether person-centred support and choice are affected by size and type of residential settings.

Person-centred support and community participation

An important aspect of the quality of support for people with ID is social inclusion and how people spend their time during the day, for example accessing the community and participating in leisure activities. Despite community participation being a key feature of government policy (Department of Health, 2009), it has been argued that many people with ID in the UK particularly those with complex needs and lower adaptive behaviour continue to have low usage of community facilities (Baker, 2000; Abbott & McConkey, 2006; McConkey & Collins, 2010). As demonstrated in the systematic review presented in Chapter 1, person-centred approaches can lead to increased community participation. Additionally, Heller, Miller, and Hsieh (2002) found that individuals with ID living in environments which promoted more choice-making also experienced higher levels of community integration.

It has been demonstrated that direct-care staff play a crucial role in promoting social inclusion and community participation (McConkey & Collins, 2010) and intuitively it could be argued that those who provide support in a more person-centred manner would also promote more community participation for the individuals they support; this relationship was explored in the present study.

Person-centred support and staff variables

It has been reported that a high percentage (25-32.5%) of paid staff working in ID services report high levels of stress and burnout, which often lead to high turnover rates (Devereux, Hastings, & Noone, 2009; Heller, 2002).

Previous research in the field of dementia has found that person-centred interventions resulted in decreased stress, strain and burnout in staff (Edvardsson, Sandman, & Borell, 2014). In the field of ID, to the researcher's knowledge, there have not been studies exploring the association between person-centred practices and difficulties faced by staff in providing care. In a study by Mansell, Beadle-Brown, Whelton, Beckett and Hutchinson (2008) it was found that compared to an intervention group which received training in person-centred Active Support, staff in the control group reported more job satisfaction at follow-up. The authors argued that the lower job satisfaction in the intervention group may have been a result of the disruption of existing arrangements caused by the introduction of the new intervention. They suggested, however, that over time staff implementing Active Support may experience higher satisfaction and better teamwork.

Another aim of the present study was to explore whether there is a relationship between the measures of person-centred support/choice and difficulty in providing care (subjective burden) experienced by staff.

Person-centred support and challenging behaviour

It has been argued that the quality of support offered by staff is a crucial predictor of residents' outcomes (Heller, 2002). As has been elucidated in Chapter 2, although, intuitively, support which is more person-centred should constitute a protective factor in the occurrence and severity of challenging behaviour, the relationship between these constructs is not entirely clear. Although specialist person-centred interventions such as PBS have been shown to reduce challenging behaviour, it is not obvious which components lead to such changes; further these interventions may not be readily

available and widely implemented in day to day care. It is unclear if non-specialist day to day care which is more person-centred is associated with less frequent/severe challenging behaviour.

The present study investigated whether there is a link between person-centred support and challenging behaviour in people with ID living in various community settings, supported by paid carers. The present study explored whether those individuals who receive care in an environment which promotes person-centred support, by staff who know them well, communicate effectively and provide individuals with more opportunity for autonomy and choice are less likely to engage in severe challenging behaviour.

The study is important as it provides a picture of the environments in which challenging behaviour is more likely to occur and it could provide an indication of the relationship between quality of care and challenging behaviour in people with ID, if such relationship exists. If a relationship between person-centred support and challenging behaviour is found, this could provide an indication on ways to prevent the occurrence of challenging behaviour by teaching and training staff in better approaches for the provision of care for people with ID.

The study also contributes to the evidence base regarding person-centred support which is critically needed due to the scarcity of empirical research investigating its relationship with outcomes, including behavioural outcomes. Additionally since the evidence base for person-centred approaches is particularly scarce in people with ID the present study, even though exploratory rather than definitive, makes a substantial contribution to the field by extending the knowledge that we have about person-centred support to other populations.

As previous studies have not clearly elucidated the nature of the relationship between choice and challenging behaviour in people with ID, the present study further explored this relationship by using more appropriate measures than used in some previous studies, in a relatively large sample size. If a relationship between choice availability

and challenging behaviour does indeed exist, there are several practical advantages to promote and embed choice within daily routines. Promoting choice is quite straightforward and simple, does not require extensive training and can be implemented within the service-users' living environment (Kern et al., 1998). Small every day choices are unlikely to have major cost implications or challenge the system of care and it should therefore be easy to act upon these choices and for staff to provide support in their implementation. It is often the small choices regarding everyday activities that really enhance the life of an individual (Parley, 2001).

Aims of the present study

- To explore the level of person-centred support/choice provided by a sample of paid carers for people with ID and challenging behaviour in community settings
- To explore whether person-centred support is associated with living environment characteristics such as size and type of accommodation.
- To explore whether person-centred support/choice is associated with individuals with IDs' community participation.
- To explore whether person-centred support/choice is associated with carer related variables
- To explore whether there is an association between the quality of support provided by paid caregivers to adults with ID and the occurrence of challenging behaviour displayed by the care-recipients, in particular to determine if, in general, providing support in a person-centred manner is associated with challenging behaviour in people with ID.
- To clarify the relationship between challenging behaviour and a specific domain of person-centred support which is opportunity for choice-making in everyday life.

Hypotheses

- There will be an inverse association between size of accommodation and person-centred support/choice. Person-centred support/choice scores will be higher in smaller homes.
- There will be a positive association between person-centred support/choice and individuals with IDs' community participation.
- There will be an inverse relationship between person-centred support/choice and paid carers' subjective burden
- There will be an inverse relationship between person-centred support/choice and challenging behaviour.

Method

The present study recruited participants who already took part in the PBS study (Hassiotis et al., 2014) and used part of the data collected during the trial in addition to data collected for the purpose of the present investigation (see Preface, p.10).

Design

The study had a cross-sectional design. Data were collected at one time point around the 12 months follow-up assessment of the PBS study.

Recruitment and Participants

The process of recruitment of participants and the resulting sample have been described in the previous chapter (p.83, 91-92, Table 3.1 and 3.2).

Measures

The measures used in the present study were those described in the previous chapter (Individualised Care, Tool for Understanding Residents' Needs as Individual Persons, Resident Choice Assessment Scale) as well as measures collected during the PBS study (see Appendix C1), which were:

Demographics questionnaire. This has been described in Chapter 3, p. 84.

Aberrant Behaviour Checklist (ABC; Aman et al., 1985). The ABC measures the severity of a person's challenging behaviour and is completed by a proxy respondent. Items on the ABC are scored from 0 to 3 with higher scores indicating more challenging behaviour. The ABC scores can be separated into five different factors comprising (I) Irritability, Agitation, Crying (15 items), (II) Lethargy, Social Withdrawal (16 items), (III) Stereotypic Behaviour (7 items), (IV) Hyperactivity, Non-compliance (16 items), and (V) Inappropriate Speech (4 items). A total score can be obtained by adding up all domain scores, although the authors of the scale have been critical of this practice as they argued that the subscales are independent of each other and calculating a total score is a meaningless summation (Aman, 2012). Nevertheless the ABC (even as a single scale) has been widely used and the measure has demonstrated acceptable reliability and validity.

Short form Adaptive Behaviour Scale (Hatton et al., 2001). This is a short version of the Adaptive Behaviour Scale-Residential and Community: Second Edition (ABS-RC2) Part I (Nihira et al., 1993); it includes 24 items of the original measure's ten domains 1) Independent Functioning; 2) Physical Development; 3) Economic Activity; 4) Language Development; 5) Numbers and Time; 6) Domestic Activity; 7) Prevocational/Vocational Activity ; 8) Self-Direction; 9) Responsibility; 10) Socialisation. In the present study the two items pertaining to language development were used as a crude measure of communication skills.

Guernsey Community Participation and Leisure Activities Scale (GCPLAS; Baker, 2000). The instrument was designed to gather information of people with IDs' use of community and leisure facilities. The GCPLA consists of a checklist of 35 potential contacts/activities arranged under six categories of activity (services, public transport, indoor leisure, leisure, sport and recreation, social facilities/amenities). The individual or proxy respondent (e.g. carer) is asked to indicate the frequency of contact or

participation over the previous 6-month period and rate this on a five-point scale: 1 = less than every 3 months; 2 = every 3 months or more frequently; 3 = monthly or more frequently; 4 = weekly or more frequently; 5 = daily or more frequently.

The 'range' score represents the amount of contacts/activities rated as being accessed every 3 months or more frequently. The 'busy' score provides an indication of the number of very frequent activity/contacts occurring more frequently than weekly. A representation of community participation is obtained by considering the scores from categories of activities with exception of 'indoor leisure'.

Caregiving Difficulty Scale-Intellectual Disability (McCallion, McCarron, & Force, 2005).

This is a measure of paid carer subjective burden. Items are scored from 0 to 3 with higher scores indicating greater difficulty with care responsibilities. The scale is formed of three factors related to day-to-day care issues, resources and conflicts and family concerns, nevertheless the authors of the scale have argued that it is preferable to use the total score rather than the individual subscales. In the present study the total score and the first two subscales were used in the analysis. The third sub-scale 'family concerns' only contains two items and has not demonstrated good psychometric properties, therefore it was not used in its own right in the present study.

Procedure

Paid carers were asked to complete the study questionnaires in their own time after a PBS study assessment or sent in a self-addressed envelope in the post. Participants who returned the questionnaire were thanked for their participation and given a £10 voucher.

Sample Size Calculation

A sample size calculation for the minimum required sample for multiple regressions, given a probability level of 0.05, a desired statistical power of 0.8 and a medium effect size of 0.15 indicated that with 9 predictors a minimum of 113 people were required in

the sample. This sample size calculation was based on the intention to test individual predictors based on the formula $104 + k$, where k is the number of predictors (Field, 2006). Other rules of thumb commonly used indicate using ten participants per predictor and therefore with nine predictors 90 responses would have been sufficient. For the present study it was decided to adhere to the most conservative estimate.

Statistical analysis

All data analyses were carried out using SPSS (version 23). Although the use of multiple statistical tests to examine relationships between a wide varieties of measures increases the risk of type-1 errors, it was decided not to decrease the alpha level for the reporting of significant associations for the correlational analyses. As this is exploratory work and Bonferroni corrections may be overly conservative resulting in type-2 errors (Perneger, 1998), we believed the risk was justified and multiple tests were carried out without adjustments and a p value <0.05 was used as the level of significance.

Nonetheless for consistency with the results reported in Chapter 3 a Bonferroni correction was used when multiple comparisons between groups were made (e.g. comparing choice across different types of accommodation).

Descriptive analysis

Descriptive analyses were conducted for the total scores of the support measures. The distribution of the scores of the three support questionnaires was analysed using Shapiro-Wilk's test of normality and the mean, median, standard deviation, range and 95% confidence intervals were obtained for each questionnaire.

Impact of PBS intervention on main measures

Since the present study was conducted within the context of the PBS study it was explored whether there were any significant differences in the present sample on the main measures used in this study, between participants in the intervention and those in the control arms of the PBS study. Specifically, independent sample t-tests (or the non-

parametric equivalent) were conducted to investigate whether there were any differences on the person-centred support measures' total scores and the challenging behaviour scores.

Bivariate correlations

Bivariate correlations with Spearman's rho were conducted between the support measures' total scores and i) size of residential settings (number of residents in each living environment) ii) community participation iii) carer related variables such as months experience, months acquaintance with service-users, difficulty in day-to-day care and iv) service-users' adaptive behaviour and communication skills

Comparisons between groups: type of accommodation and person-centred support/choice

One-way between subjects ANOVAs were conducted to test whether there were significant differences in the total scores on the two holistic person-centred support measures (IC and TURNIP), the total score of the choice measure (RCAS) and the different accommodation types (individual supported living, group supported living and residential care homes). Shapiro-Wilk's test of normality and Levene's test of homogeneity of variance were conducted to assess the suitability of parametric statistical analyses to explore the differences between the groups. Where the assumption of normality was not met the non-parametric Kruskal-Wallis H test was performed to explore differences between groups with equal variances. Where in addition to the assumption of normality, the assumption of homogeneity of variance was also violated an ANOVA with Welch's correction was applied. Post-hoc pairwise comparisons with Bonferroni corrections were performed to elucidate any significant differences across the groups.

Further analyses controlling for the potential confounding effect of adaptive behaviour were conducted by running multiple linear regressions with the support measures as

dependent variables and adaptive behaviour and supported living dummy variables as predictors.

Multiple regression analysis: person-centred support and challenging behaviour.

A series of hierarchical multiple regression analyses were conducted to investigate the relationship between person-centred support and challenging behaviour in people with ID, where person-centred support was the main predictor and challenging behaviour the dependent variable. Separate models were explored for each of the person-centred support and choice total measures. Analyses were also conducted for each of the person-centred support measures' subscales and each domain of challenging behaviour. Due to the high number of multiple regressions conducted, for the subscales, only models with significant results are reported in the results section and all other models are available from the researcher.

For each model Step 1 included participants' personal characteristics which previous research have shown to be associated with challenging behaviour such as the presence of autism, adaptive behaviour, gender and age. Step 2 included type of accommodation (individual supported living, group supported living or residential care homes). As most participants lived in residential care homes this was used as the reference category and dummy variables for individual and group supported living were included in the model. The final steps included a categorical variable indicating whether a participant received PBS or not in the PBS study and a measure of person-centred support (IC, TURNIP or RCAS).

Regression diagnostics

For each regression model the assumptions of the General Linear Model (GLM) were tested. The residuals of each model were analysed using Shapiro-Wilk's test of normality to assess if they were normally distributed. A significant result indicates that the residuals are not normally distributed and therefore the data requires transformation. Where this was the case the dependent variables were subject to

square root transformation in the first instance or log 10 transformation where the model with the square root still did not meet GLM assumptions (Field, 2005). Homoscedasticity was examined for each model by observing the residual scatter plots. In plots where the data points seem to be randomly distributed with a fairly even spread of residuals at all predicted values we can assume that the assumption of homoscedasticity is met. Multicollinearity (when there is a strong correlation between variables) was assessed by examining the average variance inflation factor (VIF) for each model. If the average VIF is substantially greater than 1 the regression may be biased. Variables with VIFs greater than 10 are cause for concern and were removed from the model and the average VIF recalculated.

Ethical considerations

This was considered a low risk study, however it was considered that participants i.e. paid carers, may have found some of the questions distressing or anxiety provoking as they related to the way in which they provide care and may have led some participants to question themselves and whether they were providing care adequately. Participants were however informed that they were free to withdraw from the study at any time and that their answers were strictly confidential.

Ethical approval

Ethical approval was granted by the UCL Research Ethics Committee (Project ID 3847/002; see Appendix C2 for letter of approval)

Results

Descriptive analysis

The results hereafter described are based on the same sample which has been described in the previous chapter (p. 91-92).

The scores on the person-centred support measures were considerably high across the sample and all measures were positively skewed as can be observed in Figures 1,

2 and 3 in Appendix C3. Shapiro-Wilk tests of normality indicated that none of the measures were normally distributed as shown in Table 4.1.

Table 4.1. Person-centred support measures descriptive statistics

Variable	Possible range	Range	Median	Mean	95% C.I.	SD	Shapiro-Wilk statistic
IC total	37-153	96-151	134	131.45	129.15-133.75	12.10	.967*
TURNIP total	30-120	78-120	109.50	107.93	106.35-109.51	8.28	.941**
RCAS total	18-126	26 -126	105.50	99.97	96.05-104.45	21.71	.875**

* $p < .05$. ** $p < .001$

Impact of PBS intervention on main measures

Mann Whitney U test showed that there was no significant difference for any of the person-centred support measures' total scores between participants in the intervention group of the PBS study and those in the control group as summarised in Table 4.2.

Table 4.2. Mann Whitney U tests

Variable	Median TAU	Median PBS	U	p
IC total	134.00	134.00	1459.00	.877
TURNIP total	108.48	110.00	1446.00	.813
RCAS total	104.56	106.04	1374.50	.608

In line with the results of the PBS study (Hassiotis et al., in press) challenging behaviour scores in the present sample were also not affected by the PBS intervention. An independent samples t-test showed that no significant difference in the ABC scores for challenging behaviour was found between participants who received PBS ($M=49.47$) and their counterparts in the control arm ($M=52.59$), $t(107)=.600$, $p = .550$.

Bivariate correlations

Person-centred support and size (number of residents) of residential settings

The number of residents in each living environment ranged from 1 to 62 with a median of 4 residents per facility and a mean of 5.7.

Bivariate Spearman's Rho correlations (non-normally distributed variables) indicated that although there were inverse associations between the size of the residential settings and the total IC score $r_s = -.150$, $p=.132$, as well as the total TURNIP score, $r_s=-.144$ $p=.148$, (higher levels of person-centred support in smaller settings), these were not statistically significant; a significant inverse association was found between the size of the residential settings and the total choice score, $r_s=-.209$, $p=.035$, indicating that choice availability was higher in smaller residential environments. This relationship subsisted even when controlling for residents' adaptive behaviour as shown in Table 4.3.

Table 4.3. Choice and size of accommodation (controlling for adaptive behaviour)

Choice	B	SE B	B	ρ
Predictor variables				
Constant	14.76	1.93		.000
Adaptive Behaviour	.186	0.34	4.88	.000
Number of residents	-2.60	.107	2.21	.017

Person-centred support and community participation

Table 4.4 shows that Spearman's rho correlations showed significant associations with community participation, specifically individuals who received more person-centred support and choice also benefited from more frequent contacts/activities in the community. The range of community contacts/activities was significantly associated with individuals' opportunities for choice-making.

Table 4.4 Person-centred support and community participation

Variables		r_s	p
Community participation 'range'	IC total	.090	.350
	TURNIP total	.179	.062
	RCAS total	.277	.004
Community participation 'busy'	IC total	.236	.013
	TURNIP total	.252	.008
	RCAS total	.285	.003

All associations remained significant even when controlling for individuals with IDs' adaptive behaviour except for the relationship between community participation and the TURNIP total score (see Appendix C4).

Person-centred support and carer variables

As shown in Table 4.5 Spearman's rho correlations showed that the measures of person-centred support and choice were not significantly associated with the length of carers' experience in working with people with ID, or with the length of acquaintance between the paid carers and the service-users.

There were significant inverse correlations between the IC total and the Carer Difficulty Scale (CDS) total score as well as the Resources and Conflicts domain of the CDS which indicated that carers who scored higher on the IC, experienced less difficulty in providing care, particularly with perceived lack of resources in their work environment and with conflicts with and between services users. This relationship was examined further to see if any particular subscale of the IC was the driver of this association and indeed it was found that the factor 'Positive feelings' of the IC had the strongest correlation with the 'Resources and conflicts domain' of the CDS ($r_s = -.234$, $p = .016$).

Table 4.5. Person-centred support and carer correlates

Variables	(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
(1) IC total	1							
(2) Turnip total	.615**	1						
(3) RCAS total	.279**	.346**	1					
(4) Months experience	.120	.166	.099	1				
(5) Months acquaintance	-.097	.043	-.104	.360**	1			
(6) Carer Difficulty Scale (tot)	-.194*	-.118	-.036	-.103	-.050	1		
(7) Day-to-day care	-.149	-.036	-.102	-.143	-.036	.971**	1	
(8) Resources and conflicts	-.241*	-.021	.126	-.021	-.021	.660**	.499**	1

* $p < .05$. ** $p < .001$

Person-centred support and service-users' adaptive behaviour

The two holistic measures of person-centred support were not significantly associated with service-users' adaptive behaviour (IC: $r_s = -.070$, $p = .469$; TURNIP: $r_s = .068$, $p = .485$) or their communication skills (IC: $r_s = -.048$, $p = .620$; TURNIP: $r_s = .051$, $p = .600$).

Associations between the measure of choice availability for the service-users and their adaptive behaviour ($r_s = .469$, $p < .001$) and communication skills ($r_s = .328$, $p = .001$) were both statistically significant.

Comparison between groups: type of accommodation

Shapiro-Wilk's test of normality and Levene's homogeneity of variance indicated the need for non-parametric analysis (see Appendix C5.). Kruskal Wallis H tests were conducted to compare the effect of the different accommodation types on the total scores of the measures of person-centred support and choice. The results indicated that there was no significant difference between the different types of accommodation for the IC total score, $\chi^2(2) = 2.34$, $p = .310$, or the TURNIP total score $\chi^2(2) = 3.83$, $p = .147$.

A significant effect of type of accommodation was found on choice $\chi^2(2) = 12.09$, $p = .002$ and this was further explored via pairwise comparisons; the Bonferroni adjustment was used to counteract the problem of multiple comparisons and the significance level was

therefore set at $p=.016$. A Mann Whitney U test revealed that there was significantly lower choice in residential care homes ($M=94.58$, $SD=22.65$) than in group supported living ($M=107.90$, $SD=19.94$); choice in individual supported living ($M=105.91$, $SD=16.90$) was not significantly different from either categories.

Nevertheless a subsequent regression analysis indicated that when controlling for adaptive behaviour, choice was significantly higher in both individual and supported living compared to residential care homes as can be seen in table 4.6.

Table 4.6 Choice and type of accommodation (controlling for adaptive behaviour)

Choice	B	SE B	B	ρ
Predictor variables				
Constant	71.89	4.50		.000
Adaptive Behaviour	.450	0.76	4.85	.000
Individual supported living	11.82	4.54	2.21	.010
Group supported living	9.79	4.37	2.07	.027

Multiple regressions: person-centred support and challenging behaviour

The results of the hierarchical multiple regression for each model have been summarised in Tables 4.7, 4.8 and 4.9. Since the first two steps are identical for all three models these are only reported in table 4.7. Tables 4.8 and 4.9 report the third and final step for the model.

Although in the original analysis plan, described in the methods section, it was decided to include the treatment arm from the PBS study as an independent variable, the decision was reconsidered and the variable was removed from the models as the results from both the present study and the PBS study (Hassiotis et al., in press) indicated that this had no effect on challenging behaviour, and therefore its inclusion in the model would be redundant. The assumptions of the GLM were met for each model and these are reported in Appendix C6.

As can be seen in the results of the multiple regressions reported in the tables below none of the total scores of the measures of person-centred support or choice were significant predictors of challenging behaviour when controlling for other confounders. In all models age appeared to be the only personal characteristic that constituted a significant predictor of challenging behaviour, with younger individuals displaying higher levels of challenging behaviour compared to their older counterparts. The results also indicated that even when controlling for other variables, challenging behaviour appeared to be significantly lower in group supported living accommodation compared to residential care homes.

Table 4.7 Results of the hierarchical multiple regression (IC total and challenging behaviour)

Block	<i>R</i>²	<i>R</i>² change	<i>p</i> <i>F</i> change	Beta	<i>p</i>
Predictor variables					
Step 1	.119	.119	.010		
Constant				80.13	.000
Autism				5.70	.269
Adaptive behaviour				-.146	.172
Gender				-2.54	.636
Age				-.532	.003
Step 2	.179	0.60	.028		
Constant				79.01	.000
Autism				8.59	.097
Adaptive behaviour				-.110	.294
Gender				-.646	.903
Age				-.459	.010
Individual Supported living				-12.08	.059
Group Supported living				-15.02	.017
Step 3	.195	.016	.158		
Constant				116.09	.000
Autism				9.05	.082
Adaptive Behaviour				-.116	.268
Gender				-.836	.874
Age				-.441	.013
Individual Supported living				-11.16	.080
Group supported living				-15.36	.015
IC Total				-.288	.158

Table 4.8 Results of Step 3 of the multiple regression (TURNIP total and challenging behaviour)

Block	<i>R</i> ²	<i>R</i> ² change	<i>p</i> <i>F</i> change	Beta	<i>p</i>
Predictor variables					
Step 3	.188	.009	.295		
Constant				11.89	.001
Autism				8.17	.115
Adaptive behaviour				-.103	.326
Gender				-.805	.879
Age				-.440	.013
Individual Supported living				-11.01	.088
Group Supported living				-14.66	.020
TURNIP				-.316	.295

Table 4.9 Results of Step 3 of the multiple regression (Choice and challenging behaviour)

Block	<i>R</i> ²	<i>R</i> ² change	<i>p</i> <i>F</i> change	Beta	<i>p</i>
Predictor variables					
Step 3	.189	.009	.285		
Constant				88.73	.000
Autism				8.57	.101
Adaptive behaviour				-.047	.704
Gender				-.126	.981
Age				-.437	.016
Individual Supported living				-10.71	.109
Group Supported living				-13.71	.033
Choice				-.148	.285

Separate analyses were also conducted for each subscale identified in the factor analyses in Chapter 3 and for each sub-domain of challenging behaviour. The great majority of the models showed that the support variables were not significantly associated with the challenging behaviour subscales. A summary of the results is presented in table 4.10 which shows the *p* values for each support predictor for each of the challenging behaviour domains. Full SPSS outputs are available from the researcher.

Table 4.10 Summary of the results of multiple regression analyses person-centred support/choice and challenging behaviour domains

Challenging behaviour domain	Person-centred support subscale	<i>p</i> value
Irritability, agitation, crying	IC Know	.417
	IC Autonomy	.725
	IC Positive Feelings	.444
	IC Communication-SU	.442
	IC Communication-Staff	.290
	Environment and Care	.595
	Organisation	.487
	Attitudes and Knowledge	.563
	Everyday Choices	.607
	Participation in household activities	.873
Lethargy, social withdrawal	IC Know	.436
	IC Autonomy	.720
	IC Positive Feelings	.276
	IC Communication-SU	.792
	IC Communication-Staff	.277
	Environment and Care	.197
	Organisation	.174
	Attitudes and Knowledge	.492
	Everyday Choices	.020
	Participation in household activities	.940
Stereotypic behaviour	IC Know	.001
	IC Autonomy	.023
	IC Positive Feelings	.151
	IC Communication-SU	.465
	IC Communication-Staff	.158
	Environment and Care	.546
	Organisation	.208
	Attitudes and Knowledge	.460
	Everyday Choices	.089
	Participation in household activities	.366
Hyperactivity, non-compliance	IC Know	.074
	IC Autonomy	.984
	IC Positive Feelings	.320
	IC Communication-SU	.702
	IC Communication-Staff	.423
	Environment and Care	.367
	Organisation	.149
	Attitudes and Knowledge	.955
	Everyday Choices	.671
	Participation in household activities	.482

As can be observed in the above table there were three models which showed a significant association between support variables and domains of challenging behaviour (significant *p* values in bold).

For all three models however there were assumptions of the GLM which were not met (normal distribution of the residuals, homoscedasticity or both) and therefore the dependent variables (challenging behaviour domains) were subject to square root transformation in the first instance and if the GLM assumptions for the resulting model was still unsatisfactory a log10 transformation of the dependent variable was conducted.

Following the transformations of the dependent variables, the results displayed in Table 4.11 showed that every day choice was no longer a significant predictor of lethargy whereas IC-Know and IC-Autonomy still significantly predicted stereotypy.

Table 4.11. Results of the multiple regressions following transformation of the dependent variable

Dependent variable	B	SE B	<i>B</i>	<i>p</i>
Predictor variables				
<i>Lethargy SQRT</i>				
Constant	4.80	.796		.000
Autism	.540	.287	.185	.062
Adaptive behaviour	-.315	.294	-.102	.288
Gender	-.003	.007	-.052	.627
Age	-.007	.010	-.072	.458
Individual Supported living	-.530	.362	-.146	.147
Group Supported living	-.398	.348	-.115	.256
Everyday choice	-.017	.010	-.184	.092
<i>Stereotypy SQRT</i>				
Constant	6.25	1.356		.000
Autism	.549	.249	.208	.030
Adaptive behaviour	-.307	.255	-.109	.233
Gender	-.010	.005	-.181	.047
Age	-.010	.008	-.111	.232
Individual Supported living	-.346	.309	-.107	.265
Group Supported living	-.511	.301	-.163	.092
IC-Know	-.120	.043	-.251	.006
<i>Stereotypy Lg10</i>				
Constant	1.35	.255		.000
Autism	.202	.079	.300	.013
Adaptive behaviour	.005	.083	.007	.952
Gender	.000	.002	-.030	.785
Age	-.002	.003	-.091	.422
Individual Supported living	-.155	.095	-.188	.106
Group Supported living	-.088	.098	-.102	.369
IC-Autonomy	-.018	.006	-.297	.009

Discussion

Summary of results

In the present chapter the relationship between person-centred support/choice (using measures adapted in Chapter 3) and adults with IDs' living arrangements, adaptive behaviour, communication skills, community participation, challenging behaviour and their carers' subjective burden was explored.

Carers generally reported high levels of person-centred support and choice and indeed scores on all measures were positively skewed.

The results indicated that neither of the person-centred support measures were significantly associated with either size or type of accommodation, whereas choice was associated with both size and type (higher choice in smaller supported living arrangements).

All support measures were associated with the frequency of community participation and the measure of choice was also correlated with the range of community contacts/activities. The relationships were sustained even when adaptive behaviour was controlled for.

Neither the carers' length of experience of working with people with ID, nor their length of acquaintance with the service-users appeared to be associated with their delivery of person-centred support and choice. There was however an inverse association between person-centred support as measured by the IC and carers' subjective burden: carers who reported lower levels of subjective burden also reported fewer negative feelings related to their job.

The two holistic measures of person-centred support were not significantly associated with service-users' adaptive behaviour or their communication skills. There was

however a significant correlation between the measure of choice availability for the service-users and both their adaptive behaviour and communication skills.

Finally, generally no association was found between person-centred support as measured in this study and challenging behaviour. However two domains of the IC showed significant associations with one domain of challenging behaviour: carers' better knowledge of the service-user and more autonomy promotion were associated with less stereotypic behaviour displayed by care-recipients.

Findings in the context of previous literature

Slightly higher levels of person-centred support were found in living environments with less individuals, however the associations between the variables were not statistically significant. Previous literature indicated that better outcomes are usually obtained in smaller settings (Heller, 2002), however Felce (2017) reported the effect of the size of living environments on outcomes has not always been consistent. Although it was hypothesised that greater person-centred support would be found in smaller settings and that personally tailored care may be harder to achieve in bigger settings where staff have a greater number of individuals to support, the variability in size across the living environments considered in the present sample was limited. Comparing living environments of similar size within the community is likely to yield different results to community-institutions comparisons. As argued by Felce (2017, p. 193) "the fact that variation within this range might not be found to have a significant influence on outcome should not be interpreted as suggesting that greater size differences would be equally insignificant".

As hypothesised choice availability was significantly inversely associated with size of accommodation and this is in accordance with previous research which found that smaller settings were more conducive to choice and control by service-users (Emerson, et al., 2001; Stancliffe, 1997; Tossebro, 1995). From the results of previous literature choice appears to be one of the variables with the strongest link to size of

accommodation and the results of the present study confirm previous findings (Felce, 2017).

No significant difference in mean scores of the person-centred measures was found between types of accommodation, i.e. between supported living arrangements and residential care homes. This indicates that care practices do not differ significantly across accommodation types, despite the emphasis in recent years to move towards supported living. Supported living is generally believed to promote greater independence and autonomy and to allow for more choices and control compared to other living environments and this has been shown in previous research (Stancliffe, 2001; Wehmeyer, 1998). Nevertheless, in the older studies supported living arrangements were typically compared to institutional settings rather than residential care homes in the community. In the previous chapter it has been argued that the support provided in residential care homes can be just as successful and flexible as that provided in supported living (The Centre for Social Justice, 2016).

Nonetheless the present study found that even when controlling for adaptive behaviour, the scores on choice availability were lower for individuals in residential care compared to those in supported living which is suggestive that supported living arrangements may be more conducive to choice-making than residential care homes. This finding is consistent with findings from previous literature which suggest that choice and control may be the only outcomes which have consistently shown to be better in supported living compared to other types of shared accommodation (Bigby & Beadle-Brown, 2016).

As predicted the measures of person-centred support and choice were associated with the frequency of community participation. Community participation and social inclusion have become key policy requirements for people with ID (Department of Health, 2001) and it was hypothesised that there would be some parallels between person-centred support and community participation which are considered elements of good support.

Confirming results from Heller et al. (2002) the present study also found that choice-making was significantly associated with both the range and frequency of community contacts/activities, even when controlling for adaptive behaviour which previous research has shown to be a determinant of people's active participation in the community (Baker, 2000). The parallels found between the measures of support and community participation provide some evidence of the concurrent validity of the person-centred support measures.

Interestingly the carers' length of experience or length of acquaintance with the service-users did not appear to be associated with either the person-centred support measures or the choice measure. Some previous research has found that newer staff may be more enthusiastic and more committed to embracing new philosophies of care, particularly those who have finished their training shortly before starting their job (Koivula, Pauonen, & Laippala, 2000). On the other hand it could be argued that staff with more years of experience may be more qualified and have better skills in delivering care. Nonetheless in the present study no support was found for either of these arguments indicating that years' experience does not influence the level or delivery of person-centred support. The length of acquaintance with service-users was also not associated with the measures of support. Nevertheless all carers had known the service-users for more than 6 months. The shortest period of acquaintance was seven months and this may be enough time to get to know the service-users well enough to understand their likes and dislikes, habits, etc. and be able to provide care in a manner which is person-centred.

No significant association was found between the total score of the Carer Difficulty Scale and the person-centred measures. Although the associations were in the expected direction (more person-centred – less subjective burden) they were very weak. One of the domains of the CDS, specifically resources and conflicts, however showed a significant negative association with the IC, which indicates that those carers who experienced less difficulty with perceived lack of resources and in managing

conflicts within the home, were able to provide a higher level of person-centred support. Closer analysis revealed that the factor of the IC driving the association was “positive feelings” and as one would expect those carers who experienced fewer difficulties also experienced less negative feelings in their day-to-day jobs.

Contrary to what was hypothesised none of the support measures constituted significant predictors of challenging behaviour in adults with ID. Although this finding is somewhat unexpected, as it was hypothesised that more person-centred support would be negatively associated with challenging behaviour, the results indicate that this may not be sufficient to influence the occurrence of challenging behaviour. Challenging behaviour can be very complex and although direct-care staff may learn to manage and prevent some behavioural problems, in order to effectively deal with challenging behaviour, input from highly specialised services may be necessary. It has been argued that many staff who support people with ID are not equipped with the skills to effectively manage challenging behaviour and the training that they receive does not prepare them for the demands of the job (McKenzie, 2011). Complex behavioural approaches such as positive behaviour support may be the only methods that really make an important difference and show effective results in managing problem behaviour, however these require a high level of skill and specialisation. As described in previous chapters, these are unlikely to be employed in day-to-day care by direct-care staff, and in fact even when specialist staff are trained in PBS and professional guidance is available there are still challenges with its wider implementation (Hassiotis et al., in press)

Interestingly a negative association was found between stereotypic, repetitive behaviour and autonomy and knowledge of the service-user. Although one could argue that those individuals whom staff spend more time getting to know and are given more autonomy engage in less repetitive and self-stimulatory behaviour, this explanation would appear more fitting to behaviours such as irritability or aggression. It may be in fact that staff find it easier to interact, and therefore get to know and encourage the

acquisition of skills, with those individuals who display less stereotypic, repetitive and self-stimulatory behaviour (these behaviours are typically more prevalent in people with autism and people with profound and multiple disabilities whom staff could find more difficult to interact with). Nevertheless a study by Beadle-Brown, Hutchinson, and Whelton (2012) found that following the introduction of a person-centred Active Support intervention, stereotypic and self-stimulatory behaviour was the only domain of challenging behaviour that saw a significant reduction, indicating that this domain of behaviour can be affected by support practices. The authors argued that much of this type of behaviour is caused by lack of external stimulation and boredom, and therefore it is not surprising that an intervention with the scope of increasing assistance and engagement in activities would stimulate its reduction. In the present study however, contrary to what was expected no association was found with this behavioural domain and participation in domestic activities, although it could be argued that such activities may not be considered meaningful or interesting enough to service-users to divert them from self-stimulatory behaviours.

With regards to choice the present study found no association with challenging behaviour. The results previously reported in the literature have been inconclusive and no clear relationship had emerged with some studies reporting significant inverse associations (Hatton et al., 2004; Ticha et al., 2012), and others not finding any relationship between these constructs (Kearney et al., 1998, 1995b). In the present study comprehensive measures of choice and challenging behaviour were used compared to the measures used in previous studies where a significant relationship was found (Ticha et al., 2012). It could be argued that the effect of choice availability on challenging behaviour may have been too small to detect in the current sample. The study by Ticha et al. (2002) adopted a much larger sample but even then choice only explained 1% of the variance of challenging behaviour. The associations in the present study were in the expected direction and it can be argued that providing more choice has a beneficial effect on challenging behaviour, albeit this effect being extremely

modest. The present study may have not had enough power to detect such a small effect and hence the lack of any significant results. It is probable that challenging behaviour may require more complex and sophisticated techniques to manage it effectively, and although providing more choices is unlikely to have a negative impact, this is not enough.

An interesting finding from the present study is that compared to what has been commonly reported in the previous literature, personal characteristics which have been previously associated with challenging behaviour did not show any significant association with the construct (Holden & Gitlesen, 2006; McClintock et al., 2003). No gender effect was found in the present study and interestingly the presence of autism was also not related to challenging behaviour, although as expected it was related to the challenging behaviour subdomain stereotypy/repetitive behaviour. Age was the only personal characteristic that appeared associated with challenging behaviour in the present sample and as reported in previous studies younger people presented more challenging behaviour than the older ones. These findings are partly comparable to those reported in a recent population study by Bowring, Totsika, Hastings, Toogood and Griffith (2017) who did not find gender and autism to be consistently associated with challenging behaviour either. In their study, contrary to what was found in the present study, however, age did also not constitute a significant predictor of challenging behaviour. The authors argued that the reported variability of personal characteristics found in the literature may be a result of differences in sampling designs and participant age and gender ratios (Bowring, Totsika, Hastings, Toogood, & Griffith, 2017). Notably, in their study Bowring, Totsika, Hastings, Toogood and Griffith (2017) found that the most significant correlate of challenging behaviour in people with ID was the impaired ability to communicate effectively. In future investigations of person-centred support it would be fundamental to include questions about adapting communication patterns according to service-users' needs.

Finally in the present study there was a significant difference in challenging behaviour between those living in group supported living compared to those living in residential care homes. It could be argued that supported living may have some structural, environmental or organisational characteristics which differ from those in residential care homes which constitute protective factors for the occurrence of challenging behaviour. Unfortunately such factors were not explored in the present study and therefore it is impossible to make inferences about any beneficial effects of this type of accommodation. Although it is possible that there are certain characteristics inherent to supported living arrangements which have a positive effect on challenging behaviour, it is very likely that the lower levels of challenging behaviour found in this particular type of accommodation are a by-product of placing individuals with particular characteristics and needs in certain accommodation types which are thought to be better suited for them. Typically supported living is thought to be more suitable for individuals with less complex needs and it is possible that the results of the present study reflect a trend to place people with less severe challenging behaviour in such settings. Conversely residential care homes may be considered more fitting for people with higher levels of challenging behaviour as they may offer specific packages of care for this particular patient group. Indeed in the present sample of participants with challenging behaviour, the majority of them lived in residential care homes which indicates that this type of accommodation is still the favoured choice for this group of people.

Interestingly there was no difference in reported levels of challenging behaviour between those living in residential care homes and those living in individual supported living. Although one could assume that individual supported living may be more suitable for individuals with a higher level of autonomy and independence, it may also be that individual supported living is considered a viable option for individuals with high levels of challenging behaviour for whom it may be considered more appropriate to live on their own rather than sharing with other individuals. This decision may arise from a belief that people without challenging behaviour should not have to live with people

with challenging behaviour, although previous research has found that for people without challenging behaviour, living with people with challenging behaviour does not necessarily have a detrimental impact on outcomes (Mansell & Beadle-Brown, 2004a). Nevertheless this may explain why similar levels of challenging behaviour are found in individual supported living and residential care homes. Group supported living on the other hand, which may be more appropriate for people with less complex needs, may be more likely to house people with mixed needs and it has been found that for people with challenging behaviour, living in mixed settings (less than 50% of individuals have challenging behaviour) leads to better outcomes than living in congregate settings (where 50% or more residents have challenging behaviour) (Mansell & Beadle-Brown, 2004a). Unfortunately data was not collected on the characteristics of other residents sharing with participants, thus it is impossible to determine if there were differences in the compositions of residents in the different types of accommodation and if this had an impact on the presence of challenging behaviour. Additionally information was not collected on the reasons why individuals were placed in their respective homes and therefore it is difficult to determine if the differences in challenging behaviour observed in the different types of accommodation are the result of characteristics specific to the living environments or the by-product of placing individuals with certain characteristics in certain accommodation types.

Strengths and Limitations

The study was the first study to use non-observational measures of person-centred support and explore this construct quantitatively in community settings for adults with ID and challenging behaviour. This being the first use of the person-centred support measures in a sample of people with ID, the study can only be considered exploratory and the results must be interpreted with caution.

As reported in the Chapter 3 (p.91) the study elicited a higher response rate (82%) from paid carers from what is typically found in postal surveys which is on average

approximately 60% (Asch, Jedrzwieski, & Christakis, 1997). Recruitment was 96.4% of the target, which is satisfactory.

Although a power calculation was conducted and an appropriate sample size was used for the specified criteria, the study might have been under-powered to detect small effect sizes. Since this was the first use of person-centred support measures in relationship to challenging behaviour, it was impossible to determine a priori expected effect sizes and therefore power calculations were conducted with medium effect sizes. As previously mentioned an earlier study by Ticha et al (2012) only found a small effect for the relationship between choice and challenging behaviour, however the measures used in the study were inappropriate and it was believed that more comprehensive measures would have been more sensitive, thus justifying the use of a medium effect size in the power calculation. All associations explored in the present study were in the expected direction and therefore it is possible that a larger sample would have detected significant associations. Nevertheless further research is needed to address those questions.

Although the sample size could have benefited from being larger, the study covered a wide geographical area and it included a variety of services from many different care providers. Although it only included individuals with challenging behaviour it can be argued that the sample was fairly representative of this particular segment of the population.

The cross-sectional nature of the study, the lack of longitudinal data and the use of correlations and regressions as method of statistical analysis also poses a limitation as it does not allow for the demonstration of causality between the variables. This method of research enquiry however is useful in exploratory studies as it highlights associations between variables which can then be explored in further research.

A limitation which is common to studies using quantitative approaches is that data from questionnaires may not provide sufficient details to influence practice and guide

change as the content of the data may not be as rich as that collected through qualitative methods. Data from questionnaires may be useful to capture what the services are lacking but may not be useful to identify what needs to be done to improve services, due to insufficient detail.

Furthermore, as has been discussed in the previous chapter, the use of self-report questionnaires may lead to biased results. With respect to the person-centred support and choice measures, there is a possibility that responses could have been affected by desirability effects. The carers may have known what the 'correct' answer should be and although they were assured that all their responses were confidential, knowing that someone would use their data may have influenced the way they answered. Moreover, carers may not want to be critical of the service they work for and therefore may have provided more positive responses. It is also possible that carers have poor introspective awareness and believe that their support practices actually reflect those presented in the questions, even though in reality they might not. As has been suggested by Priebe, Saidi, Want, Mangalore, & Knapp (2009) respondents may over-report their input as it may show them and their service in a better light, thus providing a much more positive picture of the reality of services in England. In the present study the support measures were indeed positively skewed and did not follow a normal distribution as one may have expected. It could be that this reflects some element of desirability or it may be that carers have actually embraced the principles of person-centeredness which have been widely advocated in recent policies. If this is an accurate depiction, it provides some optimism for the delivery of support for people with ID. The self-report nature of the questionnaires leaves this qualm unresolved however an attempt to shed some light on this is presented in the next chapter in which I describe the results of an observational study which attempted to eliminate the bias conveyed by self-report questionnaires.

The measure of challenging behaviour was also a staff-completed measure and this may also constitute a source of bias. Challenging behaviour was not directly observed

by the researcher and previous research has found that there may be discrepancies between carer-reported data and direct observations (Emerson & Hatton, 1996). Moreover although the ABC is a widely used measure of treatment efficacy with good psychometric properties, many of the carers commented that some of the items were outdated (e.g. "Disobedient, difficult to control") and found it difficult to provide ratings for certain items (e.g. "Cries and screams inappropriately") as they thought their rating only applied to a part of the questions e.g. scream but not the other e.g. cry. Although there are instructions to guide completion of the measure, often respondents sought clarification of the items and said they did not know how to respond as they were not sure if the behaviour would be classified as challenging (e.g. service-user who rocks when in a good mood). Perhaps it would be helpful to have clearer definitions of how behaviour should be scored as for example has been delineated by Bowring, Totsika, Hastings, Toogood, and McMahon (2017).

Selection bias may have also constituted a limitation to the study. Although 82% of those who were invited to take part did respond, it is a possibility that those who did not participate had less involvement or interest in the lives of the care-recipients or had different views regarding care. Although there were no significant differences in terms of demographic characteristics, length of experience working with people with ID and length of acquaintance with service-users between respondents and non-respondents, non-respondents may have been less invested in the care of the service-users and may have provided support in a different manner from respondents; given the lack of information of non-respondents regarding their support practices, it is not possible to draw conclusions on this aspect.

Finally, another important limitation is the use of measures which have not been widely tested in this population group. The person-centred support measures were adapted from samples of people with dementia and this was their first use with carers providing support to people with ID. The IC measures had originally been administered in large institutions, the smallest of which had fifty-two beds, therefore the scales may have not

been appropriate in small home-like facilities for people with ID. The IC, however, was selected as it appeared to capture important elements of person-centred support which appeared to be applicable to staff working with people with ID. The TURNIP was also developed for use in residential aged care. Items were adapted for use for people with ID, however again, the psychometric properties for use in this population have not been previously tested and therefore it has not been previously determined if the use of this scale is appropriate for participants in different settings. It is also important to consider that dementia is a terminal condition whilst ID is not and this may also influence the appropriateness of the measures. The scarcity of information on the measures' psychometric properties and construct validity begs the question as to whether the measures were actually appropriate, sensitive and whether they actually measured what they were intended to. Many of the relationships that were explored in the present study, although in the expected directions did not convey the results that were anticipated. Although this could have been explained by some of the methodological limitations described above, or the actual absence of such relationships, there is a possibility that the measures were not suitable and did not in fact provide an accurate representation of person-centred support in people with ID. Further research using these tools is warranted to establish their validity and reliability with this population group. Finally, person-centred support is a multi-faceted concept and the questionnaires are unlikely to capture all its facets.

Conclusion

The present chapter presented the results of a cross-sectional study exploring person-centred support and choice in community settings. A summary of the results is presented in Box 4.1.

The study suggests that supported living arrangements with few residents may promote better outcomes in terms of choice-making for people with ID. Nevertheless person centred-support did not appear to differ substantially between supported living and residential care homes and therefore the results of the study do not provide

evidence that supported living arrangements are superior in terms of outcomes for service-users.

Environments with sufficient resources to provide adequate care may enhance staff's positive feelings in relation to their jobs. Keeping up staff morale is important as much research has found that supporting people with ID and challenging behaviour can lead to high levels of stress and burnout.

Factors such as staff's experience and length of acquaintance with service-users did not appear to be important determinants of the quality of support provided indicating that mere experience is not sufficient to provide good support.

Although service-users' personal characteristics were not associated with the holistic person-centred support measures, it was clear that those with higher adaptive behaviour and communication skills benefited from more choice opportunities. This indicates that choice-making is not comparable across the spectrum of ID and more needs to be done to extend opportunities for choice-making even to those with more severe ID.

Finally neither person-centred support nor choice appeared to be related to overall challenging behaviour although stereotypy was found to be associated with two aspects of person-centred support, namely autonomy and carers' knowledge of the service-users. This would indicate that in order to effectively support people who present with challenging behaviour a higher level of skill is required than what is currently available in community settings for people with ID. Support staff will require input and guidance from professional staff which needs to be delivered consistently and systematically (McKenzie, 2011).

The study was exploratory and it presented a number of limitations, therefore caution is warranted in the interpretation of the results. Further research is needed to determine whether these findings are valid and generalisable. Further research is also required to establish the psychometric properties of the person-centred support measures and to

verify that they are indeed appropriate tools that can be reliably used to measure this construct.

Box 4.1 Summary of the results of the cross-sectional study

- All support measures (IC, TURNIP and RCAS) were positively skewed.
- Person-centred support, choice and challenging behaviour scores were comparable across participants in the intervention and control arm of the PBS study.
- There was no association between person-centred support scores (IC and TURNIP) and size of accommodation (number of individuals in each living environment)
- Scores on the RCAS (choice availability) were significantly higher in living environments with fewer residents
- There was no difference in the IC and TURNIP scores between supported living and residential care homes
- Scores on the RCAS were higher in supported living than residential care homes
- All three support measures (IC, TURNIP and RCAS) were associated with frequency of community participation.
- There was no significant association between IC and TURNIP scores and participants' adaptive behaviour or communication skills.
- RCAS scores were significantly associated with service-users' adaptive behaviour and communication skills.
- Carers' length of experience working with people with ID and their length of acquaintance with the service-users were not associated with person-centred support or choice.
- Carers who experienced less difficulties with perceived lack of resources and conflicts with staff and service-users also experienced less negative feelings in their everyday jobs
- Total scores of person-centred support and choice were not significant predictors of overall challenging behaviour
- Stereotypy was negatively associated with carers' knowledge of the individual and increased autonomy
- There were no other significant associations between challenging behaviour domains and support measures sub-scales.

Chapter 5. Person-centred support in adults with ID and challenging behaviour: an observational study

Introduction

In the previous chapters person-centred support was explored using quantitative methods. Self-administered questionnaires pertaining to the support provided to people with ID were completed by paid carers, who generally reported high levels of both person-centred support and choice availability. Previous research however has found that often responses provided by paid carers are not always in consonance with findings from other methods of inquiry. For example Reid et al. (1999) found that when asking carers to indicate the preferences and choices of people with severe ID that they supported, those expressed by staff did not correspond to those which people with ID consistently approached when given the opportunity to do so. Reid et al. (1999) argued that staff tended to overestimate the care-recipients' preferred activities/objects, food etc. and they argued that relying solely on staff's opinions may lead to inaccurate findings. Joyce, Mansell and Gray (1989) also found that when comparing staff self-completed diaries describing the activities of people with ID to results from direct-observations, concordance rates were not satisfactory. As discussed in the previous chapters, self-report questionnaires can be subject to bias (e.g. desirability) and therefore may not provide an accurate reflection of reality. The results of the previous cross-sectional study were suggestive of high levels of person-centred support and choice which may have been the result of desirability effects. In order to reduce the likelihood of inaccurate and simplistic findings Oakes (2000) argued that in the study of residential environments it is more appropriate to include multiple perspectives and it

was therefore decided to triangulate findings of the cross-sectional study with a further observational study.

When individuals, such as people with ID, may not be able to respond (or respond fully) to questionnaires or interviews and therefore are not able to provide a comprehensive account of their own subjective experience, direct observation can provide an alternative perspective to questionnaires completed by proxies (e.g. carers) (Mansell, 2011); direct observations may provide a more objective and truthful depiction of the lived experiences of those being observed, which is not filtered through the responses of proxies (Mansell, 2011).

Observations are a useful method of inquiry even when people are able to participate in interviews and questionnaires to report their own experiences. Previous research has reported that people with ID have a tendency towards acquiescence and to provide responses that they perceive to be desirable (Gilbert, 2004; Stalker, 1998). Furthermore, it has been highlighted that people with ID may have had limited exposure to alternatives and therefore have low expectations of services (Mansell, 2011); they may also be reluctant to be critical of services that support them. Observations thus provide a feasible alternative to self-reports.

Naturalistic observations allow examining events and behaviours within the normal context in which they occur and their aim is to provide a comprehensive description of what occurred in the setting (Cozby & Bates, 2015). Naturalistic observations, in comparison with questionnaires, may overcome gaps between what people say they do and what they actually do (Mansell, 2011; Mays & Pope, 1995).

The aim of the present study was to observe individuals with ID and challenging behaviour in their own homes and get a better understanding of the nature of the support received in their home environments. Of particular interest were aspects of support which have been associated with person-centred principles such as

engagement in meaningful activities, choice, autonomy, and effective communication, as best practice recommendations advocate (United Response, 2016).

Most of the recent research adopting direct-observations in the field of ID have investigated the implementation of Active Support (Beadle-Brown et al., 2012; Bradshaw et al., 2004; Mansell & Beadle-Brown, 2011, 2012). Beadle-Brown et al. (2016) argued that the implementation of Active Support can be considered as a core indicator of good support and it has been considered as an essential building block which needs to be in place when supporting people with ID. The authors argued that Active Support is the best predictor of outcomes for people with ID and that it should be considered the key measure of skilled support. Given the emphasis of Active Support in previous observational research, the present study also incorporated the Active Support Measure (Mansell & Elliott, 1996).

Since the population under investigation were individuals who are known to services for their challenging behaviour, a secondary aim of the study was to gain a better understanding of the contexts in which challenging behaviours are more likely to occur and explore whether there is a relationship between the quality of support and challenging behaviour, with those individuals receiving support in a more person-centred manner displaying more or less severe challenging behaviour. Complementing the study presented in Chapter 4 the present study used direct observations to investigate the support received by service-users as well as their engagement (or not) in challenging behaviour.

Method

Participants and settings

Participants from the same population described in previous chapters (adults with ID and challenging behaviour who had taken part in the PBS study; p. 83) and whose paid carers completed questionnaires for the quantitative study were considered for the present study.

Sample sizes in previous observational studies have been very diverse ranging from individual cases to more than 100. For the present study, we considered that twenty would constitute an adequate sample size in the context of a PhD project with a qualitative component.

A combination of purposive and convenience sampling techniques were used to recruit the participants. Initially, I attempted to select participants based on the carers' previous scores on the person-centred support questionnaires. Potential participating facilities were grouped in to lower and higher person-centred support according to scores on the quantitative measures described in Chapter 3 (p. 84-88). This approach was chosen as it would allow to draw some direct comparisons between the self-report scores and the observations; furthermore it increased the likelihood of observing participants with varying levels of person-centred support. During recruitment managers from facilities within these groups were contacted first. Nevertheless a convenience sampling approach was also adopted, inviting participants within easy reach (within the London area) or those for whom PBS study assessments were still ongoing which meant visits for the observations could be combined with PBS study appointments.

Design

The design of the observational study adopted a combination of quantitative and qualitative approaches. A guided structured observation using momentary time sampling (MTS) was accompanied by detailed field notes collected during and shortly after the observational period, which provided rich and detailed descriptions of the observed events.

MTS was adopted to record specific aspects of support received by each service-user as well as any instances of challenging behaviour displayed by the participants. A 1-

minute³ interval was used to record each resident's activities, behaviour, interactions with others and choice availability. Table 5.1 shows the categories which were used for the 1-min MTS which were derived from definitions used in previous studies (Beadle-Brown, Hutchinson, & Whelton, 2012; Dean, Proudfoot, & Lindsay, 1993; Felce et al., 1998; Oakes, 2000) (a full description of the coding process can be found in Appendix D1). The categories were not mutually exclusive as an individual could be engaged in more than one behaviour at a time.

Table 5.1 MTS Categories

Category	Category description and sub-categories
Area of observation	Description of home area where individual is observed
Activity	Social Non-Social Unclear
Choice	Is service-user been given opportunity to make a choice?
Autonomy	Is SU's autonomy encouraged?
Involvement	Is SU encouraged to be involved in activities?
Interaction Staff/Resident	Assistance Praise Restraint Processing Other
Quality of the interaction	Positive Negative Neutral
Challenging Behaviour	Self-stimulatory/repetitive Aggression Self-injurious

³ A 30-seconds interval was tested in a pilot observation but I found this interval too short to record events and take accurate notes of what was happening and was therefore subsequently changed.

Field notes

During the observation period I took detailed notes on the observed events. Examples of field note topics which were used as a guide were derived from the literature and through discussion with service-users from the Camden SURGE Advocacy Project. They are illustrated in Box 5.1.

Box 5.1. Field note topics

General impressions on the running of the home

Does the environment feel homely?

Are individuals involved in household activities?

Does cleaning and tidying up by staff take priority over engaging residents in activities?

Are alternative forms of communication used if the person has complex needs?

Are activities in the house dominated by staff? (e.g. staff make decisions)

Are there prolonged periods of inactivity disengagement and boredom?

Active Support Measure

I used the detailed field notes to complete the ASM (Mansell & Elliott, 1996), a 15-item measure of support quality scored on a four-point Likert scale ranging from 0 (poor inconsistent support/performance) to 3 (good consistent support/performance). Example items from the ASM are 'Choice of activities' and 'Speech matches developmental level of service-user' (see Appendix D2 for full scale). The maximum possible score is 45 and for each person a percentage of the maximum is calculated. A classification of Active Support is given according to the percentage score as described in Mansell and Beadle-Brown (2012): high (more than 67%), mixed (between 33% and 67%) and low (below 33%).

Procedure

With the home managers' permission and the service-users' (or consultees') consent, I visited each residential settings for the period of approximately an hour to carry out observations following the procedures for observers outlined by Beasley, Hewson, Mansell, Hughes and Stein (1993)(see Appendix D3).

Observations were conducted, unless the home manager requested otherwise, before the early evening meal, as previous research indicates that this time of the day is the most representative of people's typical days and the time of the day when most in-home activity is likely to occur (Mansell & Beadle-Brown, 2011; Robertson et al., 2004)

After a short period of introduction and familiarisation with the environment/staff and residents (approximately 10-15 minutes) I observed the participant in three consecutive fifteen minutes blocks. Every minute I recorded the participant's behaviour/activity according to the codes previously presented. Individuals were only observed in the communal areas or in their rooms if their door had been left open. Personal care was not observed.

During the observation and shortly after leaving the participant's home, I also took detailed notes of the observed events and environment. At the stage of transcribing the notes, if I thought of any additional information it was also included in the data body.

I completed items from the ASM after leaving the premises and these were used as further input to reflect on the observed events. Reasons for the given scores were recorded and incorporated these into the field notes.

Inter-observer reliability

Inter-observer reliability was checked for 3/18 (16%) of the observations with two raters observing the same person at the same time. A percentage reliability statistic was calculated for the total MTS (all categories combined) and the ASM using the formula $([\text{agreements}/[\text{agreements} + \text{disagreements}]] \times 100\%)$ as done in previous research (Hastings, 1995; Ip et al., 1994; Lowe et al., 1998).

Ethical considerations

The observational study posed minimal risk. The main ethical considerations were concerning obtaining consent for the observations from the home managers and the participants with ID (see Appendix D4 for information sheets and consent forms). Where possible, informed consent was obtained from the individual with ID directly. Easy-read information sheets were provided in advance of my visit and those who were familiar with the person's communication needs such as managers or keyworkers were asked to discuss the study information with them. On the day of the observations I re-explained the study and where possible obtained informed consent from the participant. For those for whom it was not possible to obtain informed consent, a personal consultee (i.e. next of kin) or a nominated consultee were asked to advise on the person's participation in the study. Consent to conduct observations in each service was obtained by the service managers. During the observations if the person being observed had shown signs of becoming distressed as a consequence of the observer's presence, it was planned that observations would be stopped immediately, although it was not necessary to initiate this plan. Staff on shift were told that observations would be taking place and it was explained to them that their interactions with participants would be recorded. Staff were given information sheets about the study and given the opportunity to opt out. No identifiable information was collected about any member of staff or other residents present during the observations. Ethical approval was obtained by the NRES Committee London-Harrow Ethics (reference- 16/LO/1488, see Appendix D5).

Analysis

Descriptive statistics are presented for the sample. Due to the small sample size no statistical analyses were performed to explore differences between groups and therefore results from the MTS are summarised and medians and means reported.

For the ASM there were various questions that the I was unable to answer consistently across participants due to actions not being observed (e.g. demands are presented carefully, differential reinforcement for adaptive behaviour, written plans in routine use). Where actions were not observed a score of 0 was given which does not necessarily reflect poor support in general but rather it reflects support received by the person with ID during the observational period.

A thematic analysis of the field notes was undertaken following the approach outlined by Braun and Clarke (2006). Initially the field notes were read several times. This was followed by assigning codes to segments of the narrative descriptions. The software package NVivo (version 11) was used to support the data management although the coding was done manually. Data extracts pertaining to the same codes were grouped together and in turn codes were sorted into themes. Finally I reviewed the sorted data and some of the codes and themes were re-named and reorganised into themes and sub-themes.

Results

Twenty-two participants and/or their consultees were invited to take part in the study. One consultee refused for her sister to take part due to concerns with serious health issues. For two participants, consultee forms were obtained from next of kin however consent was not obtained from the service managers to conduct observations in the participants' homes; one participant cancelled the appointment due to injury after obtaining consent forms from both manager and consultee. Observations were thus conducted with eighteen participants with ID and challenging behaviour living in the community in England and supported by paid carers in residential care homes and supported living arrangements. Participants' characteristics can be found in Table 5.2.

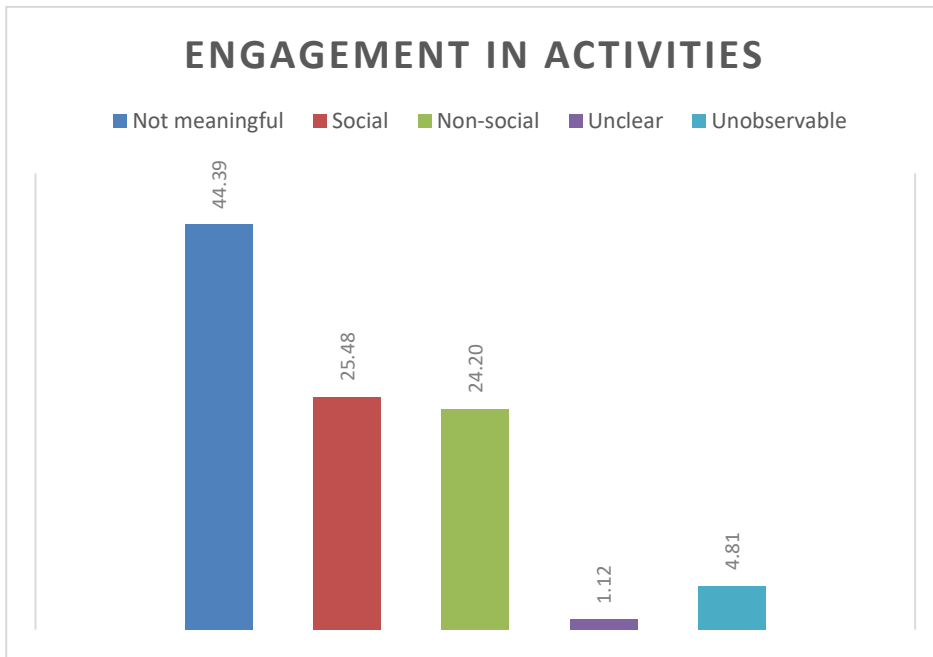
Table 5.2. Participants' characteristics

Characteristics	Mean (range) or percentage
Age	47.2 (23-78)
% Male	66.6
% Mild ID	22.2
% Moderate ID	22.2
% Severe ID	55.5
Adaptive Behaviour (SABS)	50.7 (16-96)
Challenging Behaviour (ABC)	51 (0-98)
% Expressive and receptive verbal ability	27.7
% Individual Supported living	16.6
% Group Supported living	16.6
% Residential	66.6

Momentary time-sampling

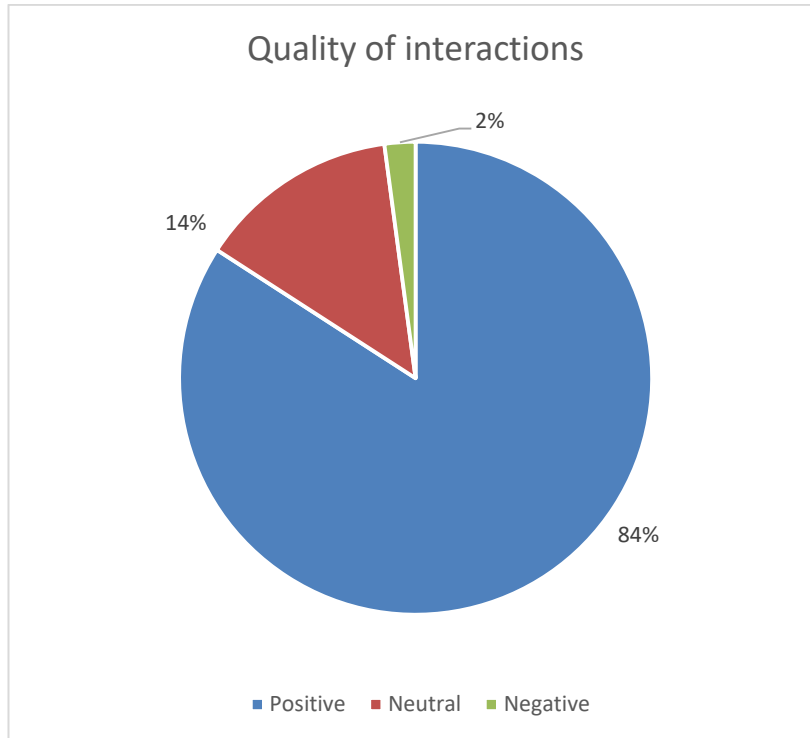
The results of the MTS show that overall for the majority of the time participants were not engaged in meaningful activities (taking part in an activity or interacting with other people in a way that is purposeful, Mansell & Beadle-Brown, 2012, p. 40). Figure 5.1 shows the percentage of intervals that participants in the sample were observed either engaged or not, and as can be seen on average the majority of time was spent not engaged. The amount of time spent engaged in social and non-social activities was comparable although there was significant variation at the individual level.

Figure 5.1 Percentage of intervals spent in different activities across the sample



Of the possible 48 observable intervals for each participant the median number of intervals in which participants had an interaction with a member of staff was 10 (20.83%); the range was however great (0-45) indicating that some participants had no interaction with staff during the observation period whereas some were engaged with staff for the great majority of the observation. The median number of intervals in which interaction in the form of assistance to engage in meaningful activity was observed was 1 (range= 0-45) and the median value for any other type of interaction (e.g. chatting with staff) was 4 (range= 0-25). The great majority of the interactions were positive with only a small percentage being described as neutral or negative, as can be seen in Figure 5.2. Negative interactions were only recorded for one participant.

Figure 5.2 Quality of interactions pie chart



Only four participants displayed challenging behaviour during the observations for a total of 81 intervals, 96.3% of which was self-stimulatory/repetitive behaviour such as head rolling, body rocking, pacing and making repetitive sounds. There were three instances of aggressive challenging behaviour which involved shouting and hitting a member of staff and these were all from the same individual

Group comparisons

When services were categorised on the basis of the level of person-centred support obtained in the quantitative questionnaires (IC and TURNIP) the results show that participants whose carers had scored higher on the measures of person-centred support spent more time in meaningful activities, were more often engaged in social activities and benefited from the most interaction with staff, particularly in the form of assistance. Table 5.3 shows the median and relative percentage of the number of intervals out of a possible 48 for each participant in which actions were observed. Participants in the low person-centred support group on average also displayed the most occurrences of challenging behaviour (mean: 19.67) compared to the medium (mean: 2.17) and high (mean: 2.25) groups. It is important to note that participants in

the low person-centred support group also had the lowest levels of adaptive behaviour and the highest staff-rated challenging behaviour.

Table 5.3 Median Engagement in activities and interactions with staff across groups categorised on the basis of staff-reported measures of person-centred support.

	Low	Medium	High
<i>Not meaningful</i>	31 (64.58%)	29 (60.41%)	2.5 (5.2%)
<i>Social</i>	4 (8.3%)	4 (8.3%)	23 (47.91%)
<i>Non-social</i>	17 (35.41%)	8.5 (17.70%)	17 (35.41%)
<i>Unclear</i>	0	0	0.5 (1.04%)
<i>Not observable</i>	6 (12.5%)	0	0
<i>Interaction with staff</i>	8 (16.6%)	9 (18.75%)	36 (75%)
<i>Assistance</i>	0	0.5 (1.04%)	21.5 (44.79%)
<i>Other</i>	2 (4.1%)	3 (6.25%)	4 (8.3%)
Mean Adaptive Behaviour (SABS)	29.67	55.83	61.75
Mean Challenging Behaviour (ABC)	86.67	50.67	32.75

Comparisons between aspects of support were also explored between different accommodation types (residential care and supported living) however no major differences were found across these categories. Differences in the nature of support received however were found when participants were categorised on the basis of their level of intellectual disability as well as their verbal abilities (verbal, some verbal ability (expressive and receptive) and non-verbal). Participants with mild ID and good verbal abilities had much lower levels of disengagement and were more engaged in meaningful activities compared to their counterparts with greater ID and limited or absent verbal abilities and had on average many more interactions with staff particularly in the form of assistance. Table 5.4 shows the median number of intervals and relative percentage in which participants with different levels of ID were observed in activities and interactions. Table 5.5 shows the median number of intervals and relative percentage of activities and interactions across participants with different levels of verbal abilities.

Table 5.4 Engagement in activities and interactions with staff across participants with different levels of ID.

	Severe	Moderate	Mild
<i>Not-meaningful</i>	20.5 (42.70%)	29 (60.41%)	1 (2.08%)
<i>Social</i>	12 (25%)	1 (2.08%)	16 (33.33%)
<i>Non-social</i>	4 (8.3%)	17.5 (36.45%)	1 (2.08%)
<i>Unclear</i>	0.5 (1.04%)	0	0
<i>Not observable</i>	0	0.5 (1.04%)	0
<i>Interaction with staff</i>	11.5 (23.95%)	2 (4.16%)	35 (72.91%)
<i>Assistance</i>	0.5 (1.04%)	0.5 (1.04%)	31 (64.58%)
<i>Mean Adaptive Behaviour (SABS)</i>	35.50.	59.50	89.33
<i>Mean Challenging Behaviour (ABC)</i>	68.75	61.50	7.33

Table 5.5 Engagement in activities and interactions with staff across participants with different levels of verbal abilities.

	Non-verbal	Some	Verbal
<i>Not-meaningful</i>	20.5 (42.70%)	36 (75%)	0.5 (1.04%)
<i>Social</i>	8.5 (17.70%)	5 (10.41%)	31.5 (65.62%)
<i>Non-social</i>	8.5 (17.70%)	0	16 (33.33%)
<i>Unclear</i>	0.5 (1.04%)	0	0
<i>Not observable</i>	1.5 (3.12%)	0	0
<i>Interaction with staff</i>	11 (22.91%)	3 (6.25%)	40 (83.3%)
<i>Assistance</i>	1 (2.08%)	0	38 (79.16%)
<i>Mean Adaptive Behaviour (SABS)</i>	35.25	68.00	92.50
<i>Mean Challenging Behaviour (ABC)</i>	71.75	33.00	11.00

Active Support Measure

The average score on the ASM was 43.58% (median: 37.77%; range: 13.33-82.22%); four participants were scored as receiving high active support, four as receiving mixed support and ten were scored as receiving low active support. Those who scored higher on the ASM also had the highest staff-rated person-centred support scores and three out of four participants had good verbal ability.

Inter-observer reliability

Inter-observer reliability was 98% on the total MTS assessment and 88% for the ASM scores.

Thematic Analysis

From analysis of the field notes five overarching themes emerged; the themes and their respective sub-themes are discussed in detail and illustrated with excerpts from the narrative descriptions. Participants' names, where given, have been changed to maintain confidentiality.

The themes related to aspects of support in the home environment and they were:

- 1) Activities
- 2) Carers' role and work
- 3) Interactions and communication
- 4) Choice
- 5) Responding to challenging behaviour

1. Activities

1.1. Waiting for the next activity/disengagement

From the observations it became apparent that for most participants, particularly those who are less independent, home time is synonymous with "relaxation" time. The great majority of the observations took part in the late afternoon in the period before the evening meal. Most participants had been out earlier in the day to a day centre or to do activities in the community with their paid carers. It was evident that the time of day when most participants returned home from their scheduled activities in the community, was not treated as an opportunity for engagement or involvement in other activities around the home but was considered as the time of the day when participants could relax while they waited for dinner. It appeared that participants' days are marked by 'special activity periods' and periods where they are left to their own devices while waiting for the next activity period, which is what was observed mostly.

Even for those participants whose observations took part at other times of the day, the time spent at home was mostly spent in a disengaged state while waiting for other things to happen, such as having lunch or going out:

Maria had been out with her support worker earlier in the day and when I arrived at the home she was sitting in her chair in the corner of the common lounge. The TV was on but she was not facing it. Maria sat in her chair for the duration of the observations, drifting in and out of sleep until the staff started getting the lounge ready for dinner. One by one, staff brought in the other residents (most of them wheelchair users) and 'placed' them in a semi-circle around the lounge. Staff laid table mats and cutlery out for residents and when asked "What do I do, do I just sit here?" staff responded that supper would be coming soon. [Observation 1].

After having a cup of tea Luke left the kitchen and went to his room. He came out of his room straight away and stood in the corridor clicking his fingers. For approximately 20 minutes he paced back and forward from the corridor to his bedroom continuously clicking his fingers and making vocalisations. During this time staff were in the kitchen not visible to the researcher. One of Luke's support workers walked up the stairs and told him "You are going for a walk soon, you have to wait". Eventually after approximately 20 minutes the support worker came and told Luke to put on his jacket as they were going out. [Observation 7]

Of the observed participants only two were involved in meaningful activities for the majority of the observation period and both of them had mild ID. Albert was involved in cleaning his room and Howard was involved in writing the shopping list, and preparing dinner; both were supported by staff.

1.2. Sedentary behaviour and limited control in own environment

From the observations it was noticed that most (N=14) participants were involved in sedentary activities. Eight of them sat in front of the TV, although only one participant (Joe) seemed to be actually watching the program. In most cases the TV was on but the remote control was not in the participants' direct view so they were reliant on staff to change the channel. Two participants were using a tablet device and one had a puzzle, the others just sat. Two participants (Ryan, Nicky) had direct access to additional alternative leisure resources such as magazines or games, however for the

majority of participants where other resources were available these were not readily accessible to them and therefore they had to rely on carers' initiatives to access them.

Roberta was sitting on the couch in the living room alone while staff were cleaning the home. The TV was on but she did not appear to be interested. When one of the staff finished mopping she went to the chest of drawers and took out a plastic bag with play dough and plastic shapes and placed it on the dining table for Roberta. Staff sat down and invited Roberta to come over. [Observation 6].

Thomas was in the living room with fellow housemates facing the TV although none of them appeared to be watching it. Staff sat beside Thomas and after five minutes asked if he would like to play chess to which Thomas agreed to. Staff got up and got the chess board from the cupboard and placed it on the coffee table in front of Thomas. [Observation 16]

2. Carers' roles and work

2.1. Support (enabling vs. doing things for)

On observation, the support provided by staff could be categorised into distinct types – 'supporting the individual' and 'doing things for the individual'. 'Supporting the individual' was characterised by involving the participant in activities, providing assistance where required in order to allow the participant to succeed, For example:

Staff asked Alex if he wanted to go and prepare a drink for himself in the kitchen. Staff supported Alex to unlock the kitchen door using hand on hand support. Alex picked orange juice from the cupboard and staff asked if he wanted his drink hot (pointing at the kettle) or cold (pointing at the sink). Alex pointed at the kettle. Alex poured the water and juice in the cup and stirred his medicine, with some hand on hand support from staff. Staff praised and encouraged Alex and prompted him to stir the cup and place the spoon in the sink. Although hand on hand assistance was provided for certain actions, staff did not make the drink for Alex but encouraged him to be involved in the process as much as he could. [Observation 11]

Howard and staff are discussing the shopping list. Howard is looking in the cupboards to see what is missing and he is telling staff what he would like to eat during the week. Howard is writing the shopping list and he is saying each item that he is writing out loud. Staff is supporting him with his spelling when required. [Observation 8].

On the other hand on most occasions staff were observed 'doing things for the individual' rather than assisting them to be involved in the process. This mostly involved preparing food/drinks, cleaning up after participants and doing the housework without involving them. This reflects a "hotel model" of care where individuals' autonomy is not encouraged and it does not appear that opportunities to teach new skills are seized.

The manager asked Thomas if he wanted a cup of tea and biscuits to which Thomas responded affirmatively. The manager called one of the other members of staff who was in another part of the house and asked him to prepare tea and biscuits for Thomas who waited in the living room. [Observation 16].

Joe walked through the kitchen and sat down at table, staff asked if he wanted a drink and prepared it for him. Once he finished his drink staff came and took the empty cup from him. [Observation 15].

2.2. Other jobs

From the observations it was noticed that staff often were busy carrying out other jobs around participants' homes such as cooking and cleaning, which the majority of participants were not involved in.

One of the main activities that staff were preoccupied with was administrative work (nearly half the cases observed), completing paperwork such as participants' daily activities records and behaviour charts. This appeared to take up a lot of staff's time which resulted in staff spending less time supporting participants.

For the great majority of the observations Daniel and his fellow housemate stayed in the living room in silence. The TV was on but neither of the service-users appeared to be paying attention; the only member of staff on shift (lone working home) was in the office on the phone with a colleague discussing Daniel's behaviour as he had been unsettled during the night, and doing admin. [Observation 10]

Carer G, who was working on shift alone, asked if we needed her there while we observed Frank, and we explained that she should do what she normally does when they are at home. She said she had "so many things to do" admin wise so she went

upstairs to the office to finish her paperwork, while Frank remained downstairs.
[Observation 9]

Although some staff remained in the same room as the participant while completing their files, they assumed a supervisory role to “keep an eye on the service-users” rather than actively supporting them to do activities. Most often they did not interact with the participants, which inevitably left them, particularly those with more severe impairment and less independence, exposed to long periods of disengagement.

For the duration of the observation Ryan was in the living room having a cup of tea, occasionally glancing at the TV or flicking through a magazine. He was sat at the table while four members of staff were sat around another table at the edge of the living room filling out the books. On different occasions Ryan turned round to look at staff who however did not seem to notice him and continued doing administrative work.
[Observation 17]

Matt sat on couch in the lounge and another fellow resident was sitting on the couch opposite him. One member of staff was sitting at a large table completing admin work. The door to the adjacent office was closed. Matt was trying to get the attention of staff by shouting in her direction and tapping on the table. Staff was however engrossed in the paperwork and did not pay attention to him. [Observation 3]

2.3. Us/them

During the observations it became clear that in most cases, particularly where there were more than one staff working together there was clear separation between staff and participants. Often participants were left in the common areas e.g. living room while staff were busy doing chores in other parts of the homes. Staff were often seen interacting with each other and not involving the participants they were supporting and even congregating in separate areas from them, leaving participants out. Other times, although participants were physically in the same room as staff, conversations between staff continued as if participants were not present.

Staff interacted mostly with other staff before engaging with Matt. Staff were gathered round the main table behind the couches where the service-users were sitting and they were observed talking in a group about other staff issues; the service-users were listening, however, they were not involved in the conversation and were not told what

the conversation was about. Although staff were not excluding the service-users from the conversation, for example by lowering their voices so that they wouldn't hear, they were not involving them. Another member of staff walked into the living room and did not greet the service-users. He offered his colleague a biscuit but not them. [Observation 3]

Three staff and five service-users were sat around the table at the centre of the art room doing arts and crafts. The three carers were observed interacting with each other and not actively involving the rest of the service-users in their conversation. One of the staff who was telling a story was showing pictures on her phone to her colleagues but did not show the same pictures to any of the service-users. [Observation 4].

On finishing her shift a member of staff announced that she was going and said bye to the rest of her colleagues who she had been chatting with, but as she walked through the lounge where the service-users were sitting she did not say anything to them. [Observation 17]

On the other hand, with a few of the participants, particularly those whose carers had scored higher on the measures of person-centred support, staff were directly involved in supporting them, even where there were more staff on shift. For example Albert, Howard and Alex had 1:1 contact with staff for great part of the observation periods.

2.4. In charge

In the great majority of participants' homes, staff appeared to be in charge and make decisions. Only two participants Nicky and Pamela who were supported by one member of staff each appeared to have full control over their surroundings and appeared to make the great majority of the decisions in their home, with staff providing support. Examples demonstrating that Pamela was indeed in control in her own home were the fact that when I rang the doorbell she was the one that answered and let me in and also then took the initiative to offer myself and the member of staff supporting her a cup of tea that she then made independently for us.

For other participants it transpired that staff were in control particularly of what and when things happened and for example:

Matt told staff he was feeling hungry and staff responded “you will eat later, you have a meeting now”. [Observation 3]

At lunch time due to the lack of space for everyone at the same time, residents had to take turns to go to lunch. It wasn't discussed with residents who would go first, staff decided. [Observation 4]

3. Interactions and communication

3.1. Staff contact

A part from three participants (Albert, Howard and Alex) who received significant staff contact throughout the observational period, for the rest of the participants contact with staff was more limited. Some participants had intermittent periods where staff spent some time doing other activities and some time with them and for example although Joe spent a significant amount of time on his own in the living room watching TV, staff later joined him and sat beside him and chatted to him while doing admin. Similarly for Nicky, although staff did spend time doing other chores such ironing, she also spent some time interacting with Nicky and comforting her when she got upset.

Most participants however were left to entertain themselves while staff were involved in other activities. Access to different resources was however limited so most participants were observed in the common areas either watching TV, or just sitting:

For approximately 40 minutes Frank remained on the couch either lying down or looking outside the window whilst staff went to the office upstairs to complete her paperwork. [Observation 9].

Peter stayed in the dining area by himself where he sat in the corner quietly occasionally sipping on his drink but mostly staring either at the wall, the table or at his mug. For the majority of this time staff were in the kitchen. Staff 1, who had been cooking and cleaning, spent all time in the kitchen cleaning up; Staff 2 was also in the kitchen but occasionally came out to the common areas to check on residents and ask if everyone was alright. [Observation 12]

3.2. Positive and friendly tones

Although the amount of staff contact during the observations was generally limited, when interacting with participants, staff typically adopted friendly, kind, polite and respectful tones. Staff also used humour and joked with participants:

Nicky was talking about the neighbours who really upset her and she appeared to become really distressed. Her support worker sat on the arm of the chair beside her and comforted her. She asked "Why are you upset?" listened patiently and reassured her. She was very understanding and polite towards Nicky. [Observation 18]

Carer G turned towards Frank and in a friendly and humorous tone she referred to Frank "Frank, where is your jacket? You are saying you want to go out, but you are not getting ready?" Frank laughed got up and reached for his coat. [Observation 9]

Joe sat in his chair to continue watching TV. His support worker shortly after came into the living room and sat beside him. He asked questions about the TV program he was watching, laughing and trying to engage Joe in small conversation "Who is that?" "Look at that". Staff was very friendly and kind to Joe, talking with respect and always addressing him by his surname. [Observation 15].

3.3. Overreliance on verbal communication

From the observational data it became apparent that even for those participants without verbal skills staff did not use alternative means of communication to facilitate participants' understanding. For example Barbara is non-verbal and cannot read; as they went for lunch staff asked her what she wanted to eat but did not provide the means for her to express her preference:

As they sat at the table for lunch staff asked Barbara "What would you like to eat today?". She put the menu in front of Barbara for her to have a look at. The menu was however all written in text and it had no pictures and therefore Barbara could not understand what her choices could be. [Observation 5].

Staff supporting non-verbal participants were only observed using verbal communication with them even though this often resulted in no response:

Joe was sat in his chair and staff walked in the living room, greeted him and sat beside him. He asked "Where do you want to go tomorrow? What do you want to do?". Joe did not respond. [Observation 15].

Staff sat on the couch beside Alex who has limited verbal skills and mainly uses gestures to communicate. She asked him "What do you want to cook later? What do you want to eat?" but Alex did not respond. Staff were only observed using verbal communication. None of the staff were observed using gestures or alternative forms of communication such as pictures to aide interactions with Alex (e.g. easy-read pictures were not displayed in the kitchen or common areas). There was an activity board with pictures of the residents engaged in activities but this did not represent a schedule. Staff nevertheless spoke slowly, clearly and with encouraging friendly tones, using humour and smiling. [Observation 11].

4. Choice and autonomy

From the observations it transpired that choice was much more available to participants able to express their preferences verbally. Pamela and Nicky stated that they have full choice over their daily schedules, meal choices etc. and are supported by staff to plan their days. Sophia chose she would rather do her puzzle than participate in arts and crafts with the other residents, and when she asked "Can I read my book later?" staff responded "You certainly can". Nonetheless choices were often restricted by staff availability and for example Sophia expressed that she would like to go to the cinema but no staff is available to take her.

Choices for participants with more severe ID were less readily available. Staff were observed offering choices between alternative options on two occasions, where participants were presented with options and asked to point which one they preferred:

Joe was sat at the table and staff asked him if he wanted some cake. Staff brought over two different cakes and showed them to Joe and asked "What do you fancy?". Joe pointed at his preferred option [Observation 15].

Most often however staff did not provide alternatives for participants to choose from and participants' choices were restricted to yes and no answers: Examples of such are:

"Would you like to move to a different chair? [Observation 17]

"Would you like a cup of tea? [Observation 9]

It was also observed that staff often made decisions for participants without necessarily given them the possibility to opt out.

Frank was on the couch. When she finished her work Carer G came down stairs and announced "I think it's time we go out now". Carer G did not ask the residents if they wanted to go out or where they wanted to go. She just said "We are going out now, do you want to get ready". "It's time to go outside". [Observation 9].

When we got to the corner of the road Barbara walked towards the left side as if she was going to cross the road and staff redirected her to the opposite side saying "No we are not going that way, we are not crossing" "We are not going there today, we are going somewhere else". Just a further few metres down Barbara tried to cross the road again going in the direction that would take her to the park and again staff reminded her that is not where they are going today "We are not going to the park today, we can go later if you want" [Observation 5].

For those participants who were less able to communicate their choices and preferences staff took on a more dominant role with greater control over the day-to-day running of their activities. Staff appeared to take the lead in decision-making leaving little room for autonomy of participants.

5. Responding to challenging behaviour

Challenging behaviour did not occur often during the observations and on the few instances that it did staff responded in a positive manner, trying to reassure the participants, de-escalating and re-directing them.

Adam had been playing on his I-pad for approximately 25 minutes, suddenly a very loud buzzing noise came from the I-pad and the participant got distressed and dropped the device to the floor; he then came out his room and walked down the corridor, he

was very agitated and dropped the I-pad multiple times. Staff approached him with a calm tone in his voice and asked him if he would like to go to the sensory room, but Adam didn't respond and stood still in the corridor dropping the I-pad. The keyworker gently nudged his arm led him back to his room and closed the door. [Observation 2]

Thomas was sat on the chair and suddenly appeared agitated. He slapped staff that was sat beside him on the leg, perhaps to get his attention. Staff responded reassuringly and in a friendly manner, he asked Thomas what was wrong and if he wanted anything; he then proposed tea and biscuits. Thomas immediately calmed down. [Observation 16].

Only aggressive/agitated behaviour however got a reaction from staff whereas repetitive behaviour/stereotypy did not elicit any response for any of the three participants who were observed engaging in it.

Discussion

Summary of the findings

The study used direct observations to explore the nature of support that people with ID and challenging behaviour receive in their home environments. The study found that in general participants had low levels of engagement in meaningful activities, low levels of assistance to engage in meaningful activities and low contact with staff. The results from the Active Support Measure showed that more than half the participants were rated as receiving low Active Support with less than a quarter of participants receiving good Active Support during the period of observation. Staff most often did things for the individuals rather than involving them and supporting them to do things for themselves. Participants spent most of the time relaxing while staff were involved in other tasks such as cleaning, cooking or doing administrative work, a task which seemed to take up a lot of their time. Despite the scarce contact between staff and participants the quality of the interactions between them were generally positive, albeit being sporadic. Aggressive challenging behaviour was observed infrequently and the majority of

challenging behaviour involved stereotypic repetitive behaviour. Staff did not respond to this type of behaviour and were observed reacting only when physical and verbal aggression occurred.

There were nonetheless noteworthy differences in the support received at the individual level. Those with superior verbal abilities and thus better able to communicate with staff received enhanced contact with staff, particularly in the form of assistance, and were significantly more engaged in meaningful activities in which their autonomy was encouraged. Choices were also much more accessible to those with better communication abilities whereas those with greater communication impairments were rarely offered choices between alternative options. No alternative forms of communication were observed to aide interactions with those with limited verbal abilities and there was an over-reliance on verbal communication on staff's behalf, which did not yield responses from participants.

Results in the context of other studies

Many of the findings from the present study are similar to those reported in the previous literature. Low levels of engagement and staff contact, particularly in the form of assistance have been reported in other studies (Beadle-Brown et al., 2016, 2012; Felce, de Kock, & Repp, 1986; Felce & Perry, 1995b). The activities that participants were engaged in, as found in Beadle-Brown et al. (2015) typically required little support from staff (e.g. watching TV, eating, drinking tea). Across the sample nearly 50% of the time was spent disengaged and only approximately 20% of the time participants were involved in interactions with staff. Nevertheless, as has been found in previous studies, there was a lot of variation across the sample with some participants having no staff contact and being disengaged for the duration of the observation, and a small number of participants being engaged and supported by staff for virtually the whole observation period. Only four participants in the sample were scored as receiving high levels of active support and this is consistent with results from previous studies indicating that

the proportion of services who consistently deliver good active support is small (e.g. 12% in Beadle-Brown et al., 2016).

Similarly to what has been reported in other studies those with higher adaptive behaviour benefited from the most participation and support compared to their less abled peers who are arguably most in need and are most reliant on staff (Beadle-Brown et al., 2016; Clement & Bigby, 2010; Felce & Emerson, 2001; Felce & Perry, 1995b). In the present study participants' verbal abilities appeared to be an important predictor of staff contact, assistance, choice and engagement with those with better verbal abilities benefitting from better outcomes. Intuitively staff may find it easier to support and interact with participants with greater communication skills, as it is easier for staff to provide choices, assess their preferences and give instructions and explanations that can help the individuals engage in tasks. Nevertheless previous research has found that when given appropriate support even individuals with more severe ID and complex needs can participate in activities, communicate, express choices and show competencies in autonomy (Felce & Emerson, 2001). Accommodation type did not account for major differences in engagement in meaningful activities or interactions with staff.

In the present study, as has been reported for example by Clement and Bigby (2010), staff were often observed doing things *for* participants. This may reflect staff's perception that certain goals are just not achievable particularly for those with more severe disabilities and therefore enabling their participation may be pointless, or that it is just easier to do things for them. Perhaps they perceive their role as taking care of rather than supporting to do, however the values and attitudes of staff were not explored in this study and therefore it is not possible to determine what drove staff care practices.

It was also frequently noticed that staff often made decision for participants, particularly those with poorer expressive language, for amongst other things, when to go out and

where to go, or dinner time and what they would eat. There seemed to be a sense of acceptance of this from the participants who were often observed 'waiting' for things to happen or for staff to tell them to do something. A qualitative study by Evans and Gore (2016) however found that people with ID and challenging behaviour who were asked to describe what good support meant to them, said that being told what to do and having controlling staff was one of the aspects of support that they perceived as negative, although some seemed resigned to this happening. Involvement of service-users in decision-making has been one of the principles which has been largely advocated in recent years and although in the present study there have been examples of this being applied in practice, for many participants this was not a reality and many decisions were still made by staff without any input from the participants.

Even when there was more than one staff member on shift only a small minority of participants benefited from 1:1 contact to engage in meaningful activities as staff often congregated. This finding is not surprising as previous literature has elucidated that the mere addition of staff does not necessarily increase the attention given to service-users. Clear allocation of staff duties and having responsibility for particular residents has been shown to increase interactions with service-users (Felce & Perry, 1995b). Where the culture of support however encourages the so called "hotel model of care", increases in the number of staff may mean that rather than improving the support available for residents, staff teams merely become more efficient in executing domestic chores and other organisational aspects of the service.

Administrative duties appeared to occupy much of the carers' time which inevitably lessened the time available to support participants, particularly in smaller services where staff worked alone. This is an issue that has been mentioned by Ockenden, Ashman, Beadle-Brown, and Wiggins (2014) who have emphasised that the focus of services should be on providing good support rather than meeting perceived requirements to complete paperwork. Nevertheless in a study by Mansell & Elliott (2001) it was found that administration was the task for which staff members reported

the most consequences from service-managers. Staff reported that whether they did the paperwork or not elicited stronger responses from managers than whether they would enable service-users to participate in activities. This may be the result of a wider systemic problem (including inspectors, regulators and commissioners) which rates services based on their management practices, processes and training rather than focusing on outcomes for service-users; a study by Beadle-Brown, Hutchinson and Mansell (2008) found no association between ratings of service quality given by inspectors and those given by researchers focused on outcomes for service-users, such as levels of engagement in meaningful activity measured by observation. It appears therefore that a shift in priorities is required to improve the support received by service-users and this means a wider culture shift away from bureaucracy which spans beyond the direct-care staff level (Bigby & Beadle-Brown, 2016).

In the present study for most participants interactions were scant. Evans and Gore (2016) however found that participants with ID and challenging behaviour in their study reported that one of the most highly valued aspects of support was staff 'making time for them' and interacting with them. The same participants reported that being left alone when staff were 'too busy' doing other activities such as household chores or administrative work made them feel upset and angry. Low levels of staff contact however have been reported often in previous studies and for example Beadle-Brown et al. (2012) found that on average participants in their sample spent three quarters of their time without any contact from anyone.

Despite the low levels of staff contact, it has to be noted that the great majority of the interactions with staff, when they occurred, were rated as positive. Staff were generally kind, reassuring and warm towards participants. It is important that staff treat the people that they support with kindness and respect, and actually this is an element of care that is highly valued by service-users. In a study by Petner-Arrey and Copeland (2015) people with ID reported that having staff who genuinely care for them is a fundamental aspect of the support relationship. The quality of rapport between staff

and service-users has been considered to influence the quality of life experienced by service-users. Evans and Gore (2016) found that people with ID and challenging behaviour emphasised that one of the most valued elements of support was the kindness, politeness and friendliness of staff, and therefore the positive interactions observed in the present sample provide some optimism for the support received by participants.

It is also important to note that during the observations staff were mostly observed using verbal communication with participants, even with those with no verbal abilities. No alternative forms of communication were observed and often participants did not respond to staff's attempts at communication. These findings are consistent with those of previous observational studies where verbal communication appears to be prevalent even when communicating with individuals with no verbal skills. Beadle-Brown et al. (2015) reported that in their study 78% of individuals whom staff had rated as having no understanding of verbal language, only received verbal communication from staff. Previous research has however indicated that for people with severe ID verbal instruction is the least effective method of communication (Repp, Barton, & Brulle, 1981). It is possible that the use of ineffective communication strategies which fail to elicit responses from individuals in turn may reinforce staff's beliefs of service-users' poor abilities and consequently reinforce dependent behaviour. This may create a culture which rather than enabling service-users reinforces them to become passive recipients of care.

Mansell (2011) reported that in observational studies it is rare to observe considerable challenging behaviour and this is consistent with the findings of the present study. Although aggressive or self-injurious challenging behaviour was not observed frequently during the observations it was noticed that staff largely ignored stereotyped and repetitive behaviours and only responded to the few incidents of aggressive/destructive behaviour. Staff members' reactions were calm and reassuring with the aim to soothe and calm the person displaying challenging behaviour. This

finding is consistent with previous research from Lambrechts, Van Den Noortgate, Eeman, and Maes (2010) who found that staff often gave service-users encouragement following aggressive/destructive behaviours and they argued that the positive attention given to these types of behaviours may act as a positive reinforcement to maintain those behaviours. Conversely, previous research and the present study found that stereotypy is often ignored by staff. This may be because staff do not perceive repetitive behaviour as challenging or something that requires their intervention (Hastings, 1995). Due to the overall low levels of challenging behaviour observed in the study it is difficult to draw robust conclusions on the relationship between behaviour and support, however from the observations it was obvious that repetitive and self-stimulatory behaviour occurred in participants who were disengaged and were not participating in any meaningful activity. As argued by Beadle-Brown et al. (2012) this type of challenging behaviour is thought to occur mainly due to the lack of other forms of stimulation and increasing service-users' levels of engagement in activities can have a positive impact on the reduction of such type of behaviour.

In the present sample there was no evident difference in the delivery of care between supported living and residential care homes, although the sample size was too small to make meaningful comparisons, especially since the majority of participants lived in residential care homes.

Despite overall gains evident from community living compared to life in institutional settings reported in earlier literature, from the present study it can be concluded that the support received by many people with ID and challenging behaviour does not enable achievements of engagement, choices, autonomy and so on that are comparable to the general population. In accordance with results from previous studies, it could be argued that despite the emphasis in policy documents and recommendations there is still a long way to go before people with ID achieve ordinary lives comparable to those of the general population. The level of what is being achieved, although better than what has been described in the past, may still be

considered to leave much to be desired and falls short of the aspirations envisaged in recent policy documents such as *Valuing People Now* (Department of Health, 2009), *Transforming Care* (Department of Health, 2012) and *Care Services for people with learning disabilities and challenging behaviour* (Department of Health, 2015)

Strengths and Limitations

The study presents a number of strengths and limitations that should be acknowledged.

The study employed a mixed methods approach combining quantitative and qualitative data. Although the sample size was too small to conduct statistical analyses, it was adequate to provide rich qualitative data.

Since the study was conducted to substantiate some of the findings from the previous quantitative study a purposive sampling approach was adopted, meaning that the sample was not random and not necessarily representative. The sample was however diverse including participants from different geographical areas in England, with mild to severe ID and varying verbal skills and adaptive behaviour; since all the participants observed had a history of challenging behaviour, the results of the present study are not necessarily generalisable to individuals with ID without challenging behaviour. The results of the present study however are similar those reported in other observational studies conducted in England and can offer valid insight into the support received by individuals with ID and challenging behaviours in this country.

Inherent to the sampling approach used is the fact that certain services were selected to take part in the study on the basis of their scores on the person-centred support measures described in the previous chapter. Consequently the researcher, who was not blind to these scores, may have been influenced during the data collection by her previous knowledge and this could have introduced additional bias to the data. To control for this potential issue a sample of the observations was subject to inter-rater

reliability. The second rater did not have any prior knowledge of the participants or of their scores on the previous questionnaires when conducting the observations and the high inter-reliability scores indicate that at least for the quantitative component of the study researcher's bias was minimised.

The period of observations was somewhat brief and it only included one visit for each participant. Nevertheless the duration of each session (approximately one hour) was comparable to those reported in previous research (Mansell, 2011) and was well tolerated by participants. Although the time before the evening meal was chosen as previous studies had identified this time of the day as a period which presented the most opportunities for engagement in activities and was deemed to be sufficiently representative of service-users' days (Mansell & Beadle-Brown, 2011), it nonetheless only constituted a sample of participants' waking hours and therefore it is possible that important behaviours and support practices could have been missed.

Due to time and resources restrictions data collection was halted after eighteen observations. This however constitutes a limitation as the decision to end recruitment was influenced by external circumstances rather than achievement of data saturation (Fusch & Ness, 2015).

As discussed by Lipinski and Nelson (1974) one of the main issues with naturalistic observations is the presence of the observer. Although as argued by Mays and Pope (1995) observational research is advantageous as it can help overcome the discrepancy between what people say and what people actually do, on the other hand it can introduce bias wherein the observer is not perceived by those being observed as a neutral stimulus. Lipinski and Nelson (1974) argued that the mere presence of an observer threatens the validity of the observations as the observer constitutes a novel stimulus which changes the natural status quo. Having a researcher observe actions and behaviours may stimulate changes in behaviour in those being observed therefore

limiting the validity of the findings. Although it was impossible to completely eliminate this potential source of bias, some precautions were taken to minimise it. Before commencing the observations I spent some time with staff and participants in order to encourage habituation to my presence. During the observations interactions with staff and participants were kept to a minimum and I strived to place myself in positions from which I had a good view of the settings but that would not interfere with activities in the home. Furthermore I had built some rapport with most of the staff and participants in the study, during the previous PBS study and therefore my presence in the home environment was not entirely novel and participants had become somewhat accustomed to me.

Reactivity however was not absent. With regards to staff, on one hand it appeared that some staff acted in a socially desirable manner, knowing that the aim of the study was to observe person-centred support and interactions with service-users. It appeared that some staff had planned to engage participants in particular activities specifically during my visit (e.g. making shopping list or cleaning room) perhaps to 'showcase' their abilities and demonstrate their skills. On the other hand however, my presence also appeared to have the opposite effect: having someone else present meant that some staff seized the opportunity to engage in other activities such as domestic chores or administrative duties whilst the participants were under the researcher's 'supervision'. Although staff and participants were asked to ignore my presence of the researcher as much as possible, it can be argued that their behaviours and actions may have been somewhat influenced by my presence. At times I got the impression that staff did not want to interfere with the study and the observations of the participant in question and therefore they may have limited their interactions with them in order to not disturb.

Participants also showed some reactivity. It was noticed that particularly participants with verbal abilities wanted to interact with me, show their abilities and talk to me about their day. Although it was explained to them that they should try their best to ignore my

presence this appeared to be very difficult for some of them, who had been looking forward to the visit. It can therefore be argued that for a number of observations my presence may have influenced the dynamics in the observed homes, thus posing a threat to the validity of the results.

The influence of the presence of an observer may have been further exacerbated during the observations where inter-rater reliability for the MTS was assessed as this involved the presence of an additional researcher. The second researcher was not known to any of the participants and this may have further influenced their behaviour. It was however agreed that for a small number of observations including a second rater would strengthen the reliability of the results and therefore the presence of a second observer was justified.

It should also be noted that for the qualitative component of the study my background and experience will have subjectively influenced the data collection and data analysis and this is discussed in the next session.

Reflexivity

I believe my previous experiences working as a support worker for people with ID and as a research assistant on the PBS study which have given me the opportunity to visit many different settings in the community where people with ID live have influenced my motivations and assumptions and exerted some influence on the present study, from the field notes I took during the observations, the information that was collected, to my analysis and interpretation of the data.

Pre-observations

Prior to commencing the observations based on my previous experiences of working with people with ID in supported accommodation as well as in a research environment I had developed some pre-conceptions on the nature of support that I expected to observe.

When I first graduated with my psychology degree, I went into my first role as a support worker with no prior experience of working with people with ID and challenging behaviour. I was not aware of the challenges in working with this population and I did not receive any on the job training. At the time I was not familiar with concepts such as person-centred support and I quickly adopted the culture of the organisations I worked in: I followed the rules and routines dictated by senior staff and did not question whether the service-users that we cared for were happy with these. Decisions regarding every aspect of the service-users' lives from what to wear to what to do were made by staff and service-users were passive recipients of care. The more services I worked in the more I accepted that this was normal and since staff were always pleasant and the majority of service-users appeared content I did not question whether this was right. I do not believe the services I worked in were bad services and my former colleagues seemed to genuinely care for the people we supported, however in hind-sight I believe that the culture within those service was not conducive to enabling individuals to be active participants in their own lives.

Based on such experiences I expected to find similar situations in the homes where the observational study was conducted. When I saw the results of the quantitative study which showed that the majority of carers scored high on measures of person-centred support and choice availability I was sceptical and assumed that social desirability or little insight into their true practices may have had an impact on the carers' answers.

My knowledge of the previous literature and the consistent reporting of low levels of support reported within it also shaped my expectations of what I would observe in my study.

Data collection

During data collection I actively attempted to avoid imposing my views or pre-conceived theories on the information I gathered. However, as it is impossible to gather

information on absolutely everything that goes on at a particular time, a selective process must be applied during the data collection process, and it is possible that I may have selectively collected information consistent with my preconceptions and overlooked any counter-evidence. A pre-defined observation guide developed by researching previous literature was used in order to provide some direction on the information to collect so that it would be consistent across participants, however the use of such guide, although not strictly adhered to, may have posed some restrictions on the information captured. The study could have been improved with the use of video-recordings which would have allowed to revisit the data multiple times and capture any information that might have been missed during the *in vivo* observations.

There were also other issues during the data collection that may have influenced the quality of the data. I was consciously aware that my presence could impact participants' behaviour and although I tried to ensure I was as unobtrusive as possible (e.g. by sitting at the back of the room) this was not always possible. When participants moved for example from one room to another I followed behind and kept taking notes and although this did not appear to bother participants, it is unlikely it will have gone unnoticed.

Another concern was that I often perceived that my visits had been perceived by the managers and carers as meetings that the participants had to attend. This may have been due to the fact that on all the previous occasions in which I visited participants' homes during the PBS study, the nature of the visits had been entirely different as it involved interactions and active participation in the completion of questionnaires. Perhaps this had created the impression that even for the observations visits, participants were expected to actively take part in something and this may have created situations which may have not been entirely usual. For example, on various occasions when I arrived at participants' homes they were in their bedrooms and carers then called them to notify them that I was there to see them and that they should come out. Despite explaining that my presence shouldn't influence what they normally did at

home, I felt that this somewhat shaped dynamics and influenced routines (e.g. participants who would have otherwise stayed in their bedrooms, moved to the living room where I was). This was particularly true for participants who had capacity to consent as in order to obtain informed consent I had to explain the research study, the nature and purpose of the observations. Agreeing to be observed may have created a sense of obligation in the participants to 'provide some content' for the observations and not wanting to let me down.

Data analysis and interpretation

The process of analysis and interpretation of the data was influenced by the way I collected the data. Although during the data collection I tried to collect as much information as possible consciously trying to avoid imposing my preconceptions on the information I gathered, it is probable that the data collected was filtered by my theoretical assumptions. Consequently given that the data body on which analysis was performed was a subjective description of what I observed, it was difficult, if not impossible, to obtain full objectivity during the process of analysis.

To curtail this concern, themes and interpretation of those were checked and discussed with a second rater who had not been present during the observations. The concern, which led to revisions of some of the themes, was that various data excerpts could be classified under different themes, and where there were differences in opinion these were discussed until consensus was agreed.

My previous experience in qualitative methods had always involved working with interview transcripts; although their analysis and interpretation is still susceptible to the issues of subjectivity, an element of objectivity remains wherein at least the body of the data is fixed. In the present study, however, the data body consisted of narrative descriptions and field notes collected by myself which from the start were prone to bias, and I struggled with the concept of not being able to fully obtain objectivity and worried about the validity of the results. I have accepted however that in research which

employs qualitative methods, and even more so in research that involves naturalistic observations and approaches used in ethnographies, a degree of subjectivity is inevitable. I nonetheless endeavoured in my role as researcher to be as impartial as possible throughout the process and to provide an accurate description of the observed events.

All in all, although it is possible that my personal experience and assumptions have led to some subjectivity, I believe that my results reflected the data, and this is supported by reliability analysis. I believe that the results reported in the present study offer a valid representation of the lives of the participants in the study and describe what may be typical for many people with ID. Although the findings were not presented to participants to check their validity, when they were discussed with people with experience of working with people with ID in similar settings, they resonated with them, indicating that the events observed in the study were not atypical.

Although I found it somewhat challenging to ensure that the process of observations was rigorous and transparent, I found it very insightful and I believe that it allowed me to obtain new information that was not captured in the cross-sectional study.

Concluding remarks

The present study provided a snapshot of the lives of eighteen people with ID and challenging behaviour living in the community. Although the study presented some methodological limitations the results confirm previous findings reported in the literature. The support received by people with ID is yet to meet the expectations envisioned in recent policy documents.

The study was conducted to complement a cross-sectional study which used information provided by carers with the aim to explore the topic of person-centred support for people with ID from an alternative perspective. In the final chapter of this thesis the results of the studies are brought together and similarities and divergences

between the findings are discussed. Implications and directions for future research are also discussed.

Box 5.1. Summary of results from the observational study

- Generally participants had low levels of engagement in meaningful activities and low levels of contact with staff
- More than half of the participants had low levels of Active Support
- Less than a quarter of participants had good Active Support
- Staff often did things *for* participants
- Participants spent a lot of time relaxing
- Administrative work took up a lot of staff time
- The quality of the interaction between staff and participants was generally positive
- Challenging behaviour was rarely observed. The most common type of challenging behaviour observed was stereotypic/repetitive behaviour
- There was great variability in quality of support at the individual level
- Participants with higher adaptive behaviour and better communication skills generally benefited from more contact with staff and support to engage in meaningful activities
- Staff largely adopted verbal communication even with participants with no verbal skills

Chapter 6. Concluding remarks, implications and future directions

Summary

This PhD thesis comprises four interlinked components, developed and completed to examine aspects of person-centred support for people with intellectual disabilities. The first component consists of a systematic review of the effectiveness of person-centred planning (PCP) which explored outcomes associated with PCP and found that the approach may have a positive, yet moderate, impact on outcomes such as community-participation, choice and participation in activities. The evidence of its influence on other outcomes such as employment and behaviour was inconsistent. Overall, the evidence was limited, of low quality and did not demonstrate that PCP can achieve radical transformations of the lives of people with ID. Despite the existence of small-scale successful demonstrations of effectiveness of PCP, its clinical, cost-effectiveness and wider implementation must be investigated in large scale studies.

Notably PCP has been criticised for its focus on plans which often do not translate into action. The so called implementation gap has called for different approaches to support people with ID focused on person-centred action. Active support constitutes an example of such an approach that aims to bridge the gap between PCP process and implementation. The aim of Active Support is to enable people with ID to successfully participate in meaningful activities, however like other multi-component approaches such as Positive Behaviour Support (PBS), its successful implementation requires skilled staff and evidence shows that their uptake in everyday practice is not widespread. One of the aims of the PhD, which has been addressed in the third and fourth components, was the exploration of whether the support people with ID receive in their everyday lives by non-specialised direct-care staff, who may or may have not

received vocational training, is person-centred. The population studied consisted of adults with ID *and* challenging behaviour and it was chosen, first, because challenging behaviour has so many adverse impacts on people with IDs' lives, and second for pragmatic reasons as I was also a full-time research assistant on the PBS study, of which participants were people with ID and challenging behaviour (Hassiotis et al., 2014).

In the second component (Chapter 3) holistic measures of person-centred support, originally developed to be administered to staff supporting older adults with dementia in long-term care settings, were adapted for use by staff supporting adults with ID and challenging behaviour. A search for non-observational quantitative measures of person-centred support used in environments for people with ID had not returned any results. Since person-centred support is a philosophy of care which is not specific to people with ID, but it is prevalent across different patient groups, the search for relevant measures was extended to research with other populations (e.g. older adults). Two measures (Individualised Care and Tool for Understanding Residents' Needs as Individual Persons) were chosen and subject to principal components analysis in order to refine their structure and develop versions of the measures suitable for use in the PhD sample. Additionally, a measure of choice availability (Resident Choice Assessment Scale) which had been developed for use for people with ID in the 1980s was also updated for use in the current context of care which has changed significantly since the measure was first developed. The adapted and updated measures were then used in the third component, a cross-sectional study exploring person-centred support for people with ID and challenging behaviour in community settings (Chapter 4).

In the cross-sectional study person-centred support was explored in relation to other variables such as type and size of accommodation, resident characteristics, carer variables and challenging behaviour.

Finally, the fourth component presented in Chapter 5 consists of a mixed methodology observational study which was conducted to complement the results of the cross-sectional study and approach the topic of person-centred support from another perspective to that provided by paid carers.

The following section presents a discussion on the comparison between the findings of the cross-sectional study and of the observational study which considered person-centred support using different methodologies. The studies complemented each other and provided an opportunity to triangulate findings.

Comparing the results of the cross-sectional and observational study

The results of the cross-sectional study generally portrayed a more positive picture of the delivery of person-centred support in every-day practice than the results from the observational study. Across the sample, scores on the quantitative questionnaires were high and positively skewed. Paid carers reported high levels of person-centeredness in the day-to-day support and choices they provided to participants. A more nuanced picture though emerged from the findings of the observations suggesting that person-centred support was not embedded sufficiently in the daily lives of people with ID in their home environments. The observations found that participants received little assistance from staff, had low levels of staff contact, low levels of engagement in meaningful activities or activities which provided participants with the opportunity to exercise choices and demonstrate autonomy, although there were differences at the individual level.

The apparent discrepancy between the findings of the multiple methods approach may have a number of explanations:

- a) The results reported in the cross-sectional study may be subject to social desirability bias and therefore are not truly reflective of reality. The observations

may provide a more truthful representation of the support received by individuals with ID.

- b) The two studies captured different aspects of person-centred support. Although the various aspects of person-centred support which have been considered in the two studies represent different facets of the same construct, they are not necessarily correlated and do not necessarily follow the same distribution. Divergences reported in the results of the two studies are therefore admissible.

There was nonetheless some convergence between the findings of the two studies. Participants whose paid carers scored higher on the quantitative measures of support and choice, were indeed observed to receive the best support among participants in the observational study. Similarly, participants whose carers scored lower in the quantitative measures appeared to have lower levels of support during the observations. These findings indicate that there is an association between what was reported by the paid carers and what was observed by the researcher, despite the differences in the methodologies. Nevertheless that fact that the level of person-centred support reported by paid carers portrayed a more positive picture than that reflected by the observations suggests that the hypothesis about social desirability may be relevant.

It was surprising that, whilst from the results of the observational study it was clear that participants with higher adaptive behaviour received more support in terms of contact, assistance and choices than participants with lower adaptive behaviour, the results of cross-sectional study did not show such pattern. No significant associations were found between scores on the holistic measures of person-centred support and participants' adaptive behaviours. This discrepancy may have been due to the person-centred support scores given by carers being generally inflated and having low variability between participants.

In concordance with the results of the observations however, the results of the cross-sectional study revealed a significant association between the measure of choice availability and the adaptive behaviour of participants with ID, indicating that those with higher adaptive behaviour are consistently provided with more opportunities to make choices than those with lower adaptive skills.

A similar pattern of results was found for the relationship between person-centred support/choice and participants' communication abilities. From the observations it became apparent that participants' ability to communicate verbally had a significant impact on the quality of support received by carers. Arguably, staff may find it easier to support people who are able to communicate their needs through verbal language compared to those with limited verbal abilities (Bigby, Clement, Mansell, & Beadle-Brown, 2009). This finding, however, did not emerge in the cross-sectional study where no significant association was found between the measures of person-centred support and participants' communication skills. A clear association was found however between choice availability and participants' communication skills, with those with greater language expression and comprehension skills having more choices available to them.

In the cross-sectional study the total scores of challenging behaviour did not appear to be associated with either the total person-centred support scores or the choice availability scores. It is difficult to compare these findings with those of the observational study as in the latter only a few instances of challenging behaviour were observed. These mainly consisted of stereotyped, repetitive behaviours such as pacing or head rocking. These types of challenging behaviour were more prominent among participants who had lower levels of engagement in meaningful activities during the periods of observations. As discussed in Chapter 5, these types of self-stimulatory behaviours may be adopted by individuals to combat boredom. Stereotyped behaviour was the only domain of challenging behaviour which showed a significant association with person-centred support facets, namely carers' knowledge of the individual and

autonomy in the cross-sectional study. Although the results from the two studies show different aspects of person-centred support being associated with stereotyped behaviour, they may indicate that this aspect of challenging behaviour may be the most affected by the quality of support provided by carers.

Strengths and limitations

The strengths and limitations of individual studies contained in this thesis have been discussed in the relevant chapters. The following section will consider the strengths and limitations of the PhD project as a whole.

The project consisted of a multiple methods evaluation of person-centred support for people with ID and challenging behaviour and adds to the body of evidence by adopting a multifaceted and multi-perspective approach. Quantitative studies which used proxy completed questionnaires, e.g. by paid carers, were complemented with an additional qualitative study in which the researcher acted as an observer. Using different methodologies and approaching research topics from different perspectives strengthens the validity of the results.

The work reported in the thesis makes a significant contribution to the status of science on and research in the subject of person-centred support. The quantitative studies of the PhD were innovative as they were the first to use non-observational quantitative holistic measures of person-centred support which could be completed by carers themselves. To the researcher's knowledge there is no other non-observational measure suitable to capture this multi-faceted concept which is specific to this population group. Adapting measures of person-centred support previously used in old age care provided a new opportunity to investigate support for people with ID. Slater et al., (2017) argued that the development of standardised measures of person-centredness is essential to accumulate internationally comparable data and provide a strong evidence-base. Although the adapted measures require further refinements and

validation they provide a pivotal starting point for future investigations of person-centred support for people with ID. The use of different measures captured various facets of the multi-dimensional construct whilst conveying convergent validity.

The approach to investigating person-centred support in this thesis differed to what has been typically reported in the literature. Previous studies in this field of research have typically investigated the effectiveness of training carers in person-centred approaches such as PCP, PBS and Active Support, on outcomes for service-users, such as quality of life, behaviour, or engagement in activities. It has been demonstrated however that these approaches are not broadly embedded by direct-care staff in their everyday practice. The studies conducted for the PhD sought to investigate whether the support provided day-to-day by paid carers, who may or may have not received formalised training in the previously mentioned approaches, adheres to person-centred principles and whether it is related to other variables such as challenging behaviour. The studies provide a realistic representation of the current status of support for people with ID in the community.

At the various stages of the PhD service-user representatives from The Advocacy Project (forum for people with intellectual disabilities who provide a voice for the intellectual disability community in Camden, London) were consulted and their feedback was sought with regards to various aspects of the studies such as content, design and interpretation of results. The importance of including the perspective of people with ID in research is increasingly recognised and the fact that people with ID were involved during the research process constitutes a significant strength.

The PhD project however has a number of limitations. The corroboration of the results from the questionnaires with information from other sources (direct observations) was conducted only for a small proportion of the carers' responses. This may pose a threat to the validity of the results. An ideal study would have included observational data for

all participants whose carers had completed the questionnaires as this would have provided objective evidence of the care provided by staff but unfortunately this was not feasible in the present study.

Further, although people with ID from The Advocacy Project were involved in a consultation capacity (e.g. assessing the face validity of questions in the quantitative measures), the results of the studies do not include the perspective of people with ID themselves. The observational study aimed to offer a different perspective from that of the carers, and observational research is particularly useful when people using services may not be able to respond to questionnaires or participate in interviews (Mansell, 2011). Studies asking people with ID directly to express their views as participants are scarce (Evans & Gore, 2016) and the fact that the results of the studies conducted for this PhD did not include the views of people with ID constitutes an important limitation.

Although staff attitudes and values that have previously been shown to be important factors in determining outcomes for people with ID (Bigby & Beadle-Brown, 2016) were explored in the TURNIP (Edvardsson et al., 2011), these were not investigated comprehensively. Furthermore, whether carers work in a person-centred manner is also influenced by a number of other factors which were not explored in the present project. Factors such as training, staffing ratios, motivation, job satisfaction, staff turnover, burnout, management, etc. are all likely to exert some influence on the care practices of staff (Bigby et al., 2009). In the present project there was no exploration of the wider operational culture of the services in which carers operate e.g. staff were not asked about the pressures they might face in their jobs such as adhering to rules and regulations which may interfere with the way in which they provide support. Investigations into management practices and of the broader organisational context were also not performed, although these have been shown to have a great impact on staff practices and their adherence to home philosophy statements (Mansell & Beadle-

Brown, 2012). Although the results of the studies in this PhD provide a picture of the current state of affairs in the support received by people with ID in the community they do not offer a comprehensive explanation of *why* things are as they are.

Future directions for research

In light of the limitations presented in the previous section, directions for future research studies are suggested.

Firstly, future studies investigating person-centred support for people with ID would benefit from greater involvement from people with ID themselves. A qualitative study would be useful to explore what person-centred support means for people with ID, what aspects of support may be more valued by them and what needs to be improved in the current support received by people with ID. As argued by De Silva (2014), definitions of person-centeredness are usually coined by academics, professionals and policy makers. People with ID have not generally been involved in defining what person-centeredness means to them. Interestingly a qualitative study by Evans and Gore (2016) found that when people with ID and challenging behaviour were asked to describe the most valued aspects of support, most of the interviewed participants did not refer to aspects of good support which are typically emphasised by researchers, such as engagement in meaningful activities or autonomy. Rather participants emphasised the importance of staff behaviours that would lead to better rapport and effective relationships such as kindness and politeness. A study of their views would therefore be important as it may uncover significant areas not typically emphasised by other stakeholder groups. As reported in the NICE draft guidance *Learning disabilities and behaviour that challenges: service design and delivery* (NICE, 2017), it is necessary to explore the views of people with ID and their families on what good person-centred support looks like and what it means for them.

The views of people with ID would also be useful to develop new measures of person-centred support covering aspects of care which are meaningful to service-users. As reported by their original authors, the measures used in this study were developed after reviewing the relevant literature for constructs associated with person-centred support and by consulting with expert panels, typically constituted by other researchers and experts in the field to assess the relevance of the included items. Involving people with ID directly in the item-generation of questionnaires would allow to develop a measure of person-centred support appropriate and specific to this population group with high validity. More involvement of people with ID and exploration of their views is highly recommended in future studies.

In future research, it is also important to include, where possible, patient reported outcomes measures. Previous studies have demonstrated that information provided by proxies tends to either underestimate or overestimate responses, and proxies may not have great insight into individuals' thoughts and feelings, particularly when subjective measures (e.g. psychological well-being or satisfaction) are considered (Perry & Felce, 2002)

As previously highlighted, one of the limitations of the current project was the lack of investigation into management practices and the broader organisational context in which care is provided. Future studies investigating the support provided by direct-care staff should also consider other factors which may have a direct impact on their performance. It is important not just to describe *how* things are but to answer questions regarding *why* things are as they are. Qualitative studies with carers and managers would be useful to provide better insight into current practices. Understanding the barriers and facilitators of person-centred support is fundamental to successfully implement change.

With regards to research concerning person-centred support and challenging behaviour, future studies should consider ways to optimise the delivery and implementation of approaches which have been shown to be effective at reducing challenging behaviour such as PBS. Results of a study by McGill et al. (unpublished) indicate that intervening at the organisational level, rather than the individual level, may be a promising approach to reduce challenging behaviour in people with ID.

Implications for practice

Quality of support

The results of the studies which have explored person-centred support for people with ID and challenging behaviour suggest that there is still much work to be done to improve the support that this population group receives.

The findings from the systematic review of the effectiveness of PCP indicate that having good quality plans is not sufficient to improve the quality of life of people with ID. It is imperative that plans are followed by action and people with ID require the appropriate support in order to achieve the goals and objectives set out in the plans. This is particularly true for people with more complex needs who are more dependent on others to access opportunities. The availability of adequate support is likely to enhance or diminish their quality of life and their ability to be active participants in their own lives.

Unfortunately the results of the observations suggested that despite the numerous reports, guidelines and policy recommendations of recent years (Department of Health, 2009, 2012; NHSE, 2015; NICE, 2017), the support that people with ID and challenging behaviour receive in their home is still sub-optimal. The care practices observed during the observation periods conducted for the purpose of this PhD do not differ significantly from those reported in earlier observational studies (Beadle-Brown et al., 2016, 2012; Felce et al., 1998; Felce & Perry, 1995b). Moreover, they highlighted that there are still

many disparities within similar living arrangements which are highly influenced by service-users' characteristics, a finding which has consistently emerged in previous research (Kozma et al., 2009). This constitutes a cause for concern as it does not appear that much has changed in terms adopting the principles and philosophies that have been so widely advocated. The question remains as to *how* do we change this? What can be done to improve the support provided to people with ID who may also present with challenging behaviour?

It could be argued that frontline staff who support people in their everyday lives need to be better equipped with the skills to be able to successfully undertake the challenges involved in supporting individuals with intellectual impairments, particularly those with more complex needs and challenging behaviour. Documents such as *Transforming care* (Department of Health, 2012) and *Positive and Proactive Care* (Department of Health, 2014) which aim to shape the way services provide support for individuals with ID, have emphasised the importance of a capable workforce. Front-line staff need to be given the right training and support to enable them to provide adequate care particularly for people with challenging behaviour who often have a generally impoverished quality of life. It has been argued that classroom training is not likely to be sufficient to change actual care practices; a combination of classroom and practical 'hands-on' training appears to be more effective in increasing staff competences and improving outcomes for the individuals they support (Bigby & Beadle-Brown, 2016; Mansell & Beadle-Brown, 2012).

It has however also been argued that staff attitudes and values are just as important predictors of positive outcomes and these are less affected by training (Bigby & Beadle-Brown, 2016). Oliver et al. (2005) argued that the presence of well-established and motivated teams may be more important for improved outcomes than any treatment model per se. Therefore, making sure that the 'right' people are employed in supportive roles is fundamental. A study by Kroese and Rose (2011) emphasised the

importance of employing staff who “show a genuine interest” in supporting people and who have strong adequate inter-personal skills.

It is a well-known fact that staff supporting people with ID, particularly those with challenging behaviour experience high levels of stress and burnout (Chung & Harding, 2009; Mills & Rose, 2011). In the cross-sectional study it was found that carers who reported fewer difficulties with perceived lack of resources and with managing conflicts with other colleagues experienced more positive feelings about their jobs. Ensuring that services are well resourced and adequately equipped and having systems in place to manage conflicts effectively are important factors in maintaining staff morale. Furthermore, managers play a fundamental role in supporting staff and providing guidance to be able to respond effectively to the demands of the job (McKenzie, 2011). In the Active Support literature it has been suggested that the best outcomes are achieved when managers engage in Practice Leadership, that is, they spend time observing the work of staff, provide feedback and ongoing supervision and lead by example modelling good practice. In practice leadership managers encourage staff to improve service-users engagement and performance is reviewed in one-to-one supervision and regular team meetings (Deveau & McGill, 2016a; Mansell & Beadle-Brown, 2012). Working in this manner has also been shown to improve job satisfaction among carers (Deveau & McGill, 2016b).

Nevertheless it has been argued that often managers are torn between focusing on outcomes for service-users and meeting the expectations of external inspectors. Deveau and McGill (2016a) reported that managers felt that the amount of office-work they had to complete inhibited their ability to act as practice leaders.

Assessing the quality of support

As discussed in Chapter 5, there may be a need to reconsider the way that regulators and inspectors evaluate services and the quality of support. More importance should

be placed on service-user outcomes rather than focussing on bureaucratic processes. It is common practice that quality regulators and inspectors often use written service reports as evidence of support practices which however may not reflect actual practice. Paperwork is not necessarily an indicator of service quality and caution should be exercised when drawing conclusions on service quality based on written documentations. Much time is also spent interviewing service managers and staff about their knowledge, values and visions for the service, however, it is possible that although their verbal responses demonstrate adherence to principles of inclusion, choice, participation etc. these may not be translated into action. It may be necessary to spend more time talking to individuals and/or their family members and observing staff practices over a number of days in order to capture a 'real' sense of the quality of the support provided. Since previous research (McConkey, Sowney, Milligan & Barr, 2004) has highlighted that often people with ID are reluctant to criticise the services that support them, a useful approach would be to ask individuals if they would change anything about the service rather than directly asking them to state if they are satisfied or dissatisfied with the support they receive.

Standardised measures are typically considered the best tools to measure outcomes and their use is particularly useful to explore associations between variables, to monitor changes over time and evaluate the effectiveness of interventions. As previously mentioned it would be useful to have some valid and reliable tools to assess the quality of support. Further work on refinement of a tool measuring person-centred support in services for people with ID would be useful not only as a research tool but also as intervention tool to be used in clinical practice which would allow to highlight areas of weaknesses and strengths in services which provide support.

It is important to note nonetheless that meaningful outcomes may differ between different groups of people with ID and challenging behaviour. Typically, as argued by Clement and Bigby (2010) social policy goals are often written without any

differentiation between people with different needs. People with ID are often referred to in policy documents as if they were a homogenous group and staff may find it difficult to apply the same principles and practices used with people with moderate/mild ID to those with more complex needs, thus discounting them as irrelevant for this subgroup. Clearer guidance needs to be available for those in supportive roles to be able to improve the support they offer across the spectrum of people with ID.

Support and challenging behaviour

As reported previously, the results of the cross-sectional study showed that despite high self-reported levels of person-centred support and choice, these were not associated with overall scores of challenging behaviour, a factor which has been shown to have important consequences on the quality of life of people with ID. Both the cross-sectional and observational study showed some associations with stereotyped/repetitive behaviour. This finding is useful as it can indicate that it may be sufficient to apply some changes in the support provided in every-day practice such as providing more activities and autonomy to reduce stereotyped/repetitive behaviour. As discussed in Chapter 4 on the other hand, expert professional input by someone skilled in approaches such as functional analysis, psychological and applied behavioural analyses approaches may be required to tackle behaviours such as aggression, self-injury and other socially inappropriate behaviours. Skilled professional expertise should be widely available and readily accessible to community services which may lack the knowledge and skills to prevent and respond to challenging behaviour in an effective and consistent manner (McKenzie, 2011). Staff providing direct support should be able to access advice from behaviour support specialists promptly (NICE, 2017). As argued by Kozma et al. (2009) much research has been conducted on interventions for challenging behaviour, but now priority should be given to applying them in practice.

Despite the wealth of guidance of what changes are needed in services for people with ID and challenging behaviour, it is apparent that the quality of service delivery remains

generally low and inadequate (Carnaby, Roberts, Lang, & Nielsen, 2011). Examples of good practice however do exist and it is important to recognise these whilst continuing to strive for improvement.

Dissemination

At the time of completion of this thesis, modified versions of the following chapters had been published:

- i) A version of the systematic review presented in Chapter 1 has been published in *Research in Developmental Disabilities* (Ratti et al., 2016)
- ii) A version of the exploratory factor analysis of the Resident Choice Assessment Scale presented in Chapter 3 has been published in the *Journal of Mental Health Research in Intellectual Disabilities* (Ratti et al., 2017)

Additionally I presented elements of this research at symposiums and conferences internationally:

- i) Various oral presentations were given at different stages during the PhD at Centre for Developmental Disabilities Research seminars, UCL, London (January, 2015; May, 2015, January 2016, October 2017)
- ii) An oral presentation of the observational study (Chapter 5) was given at the Faculty of Intellectual Disability Conference 2016, London (March, 2016)
- iii) A poster of the systematic review presented in Chapter 1 and an oral presentation of the cross-sectional study presented in Chapter 4 were given at the European Association for Mental Health in Intellectual Disabilities, Florence (September, 2015)
- iv) A poster of the study overview was presented at UCL Postgraduate Symposium (pre-upgrade) in March 2015

My aim is to continue to disseminate the findings of this thesis in journal publications and conferences.

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Appendices

Appendix A (Chapter 1)

A1. Published person-centred planning systematic review

Research in Developmental Disabilities 57 (2016) 63–84



Contents lists available at [ScienceDirect](#)

Research in Developmental Disabilities



Review article

The effectiveness of person-centred planning for people with intellectual disabilities: A systematic review

 CrossMark

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ABSTRACT

Objectives: To evaluate the effectiveness of Person-Centred Planning (PCP) on outcomes for individuals with intellectual disabilities (ID) across the age range.
Method: The electronic databases PsycInfo, Embase, CINHAL, PubMed, Web of Science, Scopus and Medline were searched for studies evaluating the impact of PCP on people with ID, published between 1990 and 2014; these were supplemented by manual searches of reference lists. Studies were considered irrespective of methodology, sample size and publication source, if outcomes reflected the impact of PCP on individuals with ID.
Results: Seven quantitative, five qualitative and four mixed methods studies were included in the review. The overall quality of the evidence was low but suggestive that PCP may have a positive, yet moderate, impact on some outcomes for individuals with ID, particularly community-participation, participation in activities and daily choice-making. For other outcomes such as employment the findings were inconsistent.
Conclusion: The evidence supporting the effectiveness of PCP is limited and does not demonstrate that PCP can achieve radical transformations in the lives of people with ID. Clearer descriptions of PCP and its components are needed. Small-scale successful demonstrations of effectiveness exist, but its clinical, cost-effectiveness and wider implementation must be investigated in large scale studies.

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A2. PCP Systematic review search terms

Search terms in relation to intellectual disabilities and truncated variants

Intellectual disability

intellectual* disab*
intellectual* disorder*
intellectual* impair*

Mental retardation

mental* retard*
mental* challenged
mental* handicap*
mental* impair*
mental* deficien*

Learning disability

learning disab*
learning disorder*
learning impair*

Developmental disability

development* disab*
development* disorder*
development* impair*
subaverage intelligence

Search terms in relation to PCP and truncated variants

Person centred planning

person-cent* plan*
person cent* plan*
PCP

personalisation

personalization
individual* service* design*
lifestyle plan*
essential lifestyle* plan*
ELP
personal future* plan*
future* plan*
shared action* plan*
care management
McGill Action Plan* System
Planning Alternative Tomorrows with Hope
PATH

A3. Criteria for evaluating quality of quantitative research

Reporting	External Validity	Internal validity
1. Is the hypothesis/aim/objective of the study clearly described?	11. Were the subjects asked to participate in the study representative of the entire population from which they study subjects were derived?	14. Was an attempt made to blind study subject to the intervention they received?
2. Are the main outcomes to be measured clearly described in the Introduction or Methods section	12. Were those subjects who were prepared to participate, representative of the entire population from which they were recruited?	15. Was an attempt made to blind those measuring the main outcomes of the intervention?
3. Are the characteristics of the patients included in the study clearly described?	13. Were the staff, places and facilities where the patients were treated, representative of the treatment the majority of people receive?	16. If any of the results of the study were based on "data dredging", was this made clear?
4. Are the interventions of interest clearly described?		17. In trials and cohort studies, do the analyses adjust for different lengths of follow-up of patients, or in case- control studies, is the time period between the intervention and outcome the same for cases and controls?
5. Are the distributions of principal confounders clearly described?		18. Were the statistical tests used to assess the main outcomes appropriate?
6. Are the main finding of the study clearly described?		19. Was the compliance with the intervention reliable?
7. Does the study provide estimates of the random variability in the data of the main outcomes?		20. Were the main outcome measures used accurate (valid and reliable)?
8. Have all important adverse events that may be a consequence of the intervention been reported?		21. Were the patients in different groups recruited from the same population?
9. Have the characteristics of patients lost at follow-up been described?		22. Were the patients in different groups recruited over the same period of time?
10. Have actual probability values been reported for the main outcomes except when probability value is less than 0.001?		23. Were study subjects randomised to intervention groups?
		24. Was randomisation concealed?
		25. Was there adequate adjustment for confounding in the analyses from which the main findings were drawn?
		26. Were losses of patients to follow-up taken into account?

A4. Criteria for evaluating quality of qualitative research

1. Was reflexivity discussed (e.g. effect of personal bias on the data/participants)
 2. Was sampling of participants discussed, e.g. purposive or convenience. Did it include a range of different participants from different settings?
 3. Discussion of how data was collected e.g. face to face interviews/telephone interviews and where (home, day centre)
 4. Stated how many participants included in study
 5. Stated how many participants were approached and refused to participate
 6. Stated demographic information of participants
 7. Did they give examples of questions and prompts used in the interviews/groups
 8. Did they state how data was recorded e.g. audio-taping or hand written notes
 9. Were field notes made?
 10. Was data saturation discussed?
 11. Were transcripts returned to the participants for discussion/ feedback?
 12. Was the theoretical basis for analysis discussed e.g. thematic analysis/discourse analysis etc.?
 13. Was there more than one coder? (assessment of validity)
 14. Did they explicitly state how the coding process was done and how themes were derived
 16. Did they state the use of software to manage the data?
 17. Did participants provide feedback on the findings?
 18. Were quotations used to illustrate themes and were these identified (e.g. by participant number)
 19. Was there consistency between data reported and findings?
 20. Were major themes clearly presented?
 21. Did they discuss any deviant cases (e.g. findings that were contradictory to emerging themes)
 22. Was there triangulation of data? (e.g. between different data sources or different interview groups)
 23. Any other comments? Overall assessment of quality: strong, moderate, weak?
-

Appendix B (Chapter 3)

B1. Published Resident Choice Assessment Scale (RCAS) Exploratory Factor Analysis



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An Exploratory Factor Analysis and Construct Validity of the Resident Choice Assessment Scale With Paid Carers of Adults With Intellectual Disabilities and Challenging Behavior in Community Settings

Victoria Ratti, Victoria Vickerstaff, Jason Crabtree & Angela Hassiotis

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B2. Questionnaire pack given to participants (paid carers)

Paid Carer Information Sheet

The care environment and clinical outcomes in adults with intellectual disabilities and challenging behaviour.

This study has been approved by UCL Research Ethics Committee Project ID 3847/002

I would like to invite you to participate in my research project. You should only participate if you want to; choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, please read the following information carefully and discuss it with others if you wish.

What is the study?

The study is part of my PhD project. It is an additional project to the PBS study you have already taken part in.

The aim of my project is to explore the characteristics of the living and care environment in which people with intellectual disabilities and challenging behaviour are currently living in. It is important to investigate whether there are certain characteristics of the living environment and the care received that may act as protective factors for the occurrence of challenging behaviour. The data I will collect for my project will be used in conjunction with some of the data you have already provided during the PBS study.

Who can take part in this research?

I am inviting paid carers of people with intellectual disabilities and challenging behaviour who have already contributed to the PBS study.

What will the study involve?

If you agree to take part in the study you will be presented with a consent form to read and sign to confirm your participation agreement. You will then be asked to complete three questionnaires regarding the care environment in which you work in and the relationship you have with the service-user for whom you previously answered questions in the PBS study. Completing the questionnaires is not expected to last longer than 15-20 minutes and you will be compensated for your time with a voucher of the value of £10.00.

Is there any harm for you of taking part in the study?

There is a slight possibility that some of the items within the questionnaire could be related to topics that may cause you some distress or that you may feel uncomfortable answering. Should you experience any related worries or concerns at any point, we can discuss them and we can decide whether to

proceed with the research. If you feel you need extra support you can contact me using the contact details provided.

Your decision

I am approaching you because you have told us before that you would like to be informed of other research our team is doing. It is up to you to decide whether or not to take part. If you choose not to take part, you won't incur any penalties or lose any benefits to which you may be entitled. However, if you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. Even after agreeing to take part, you can still withdraw at any time and without giving a reason.

What will happen to the information you provide?

All data will be collected and stored in accordance with the Data Protection Act 1998. The information that we collect from you is confidential and anonymous. Only the researcher will be able to access this information.

We will produce a report of the findings and will send you a summary. Also, we will publish scientific papers based on this work. All personal information will be anonymised at all times

Contact details

Please feel free to contact me if you have any questions about the study.

Victoria Ratti

Telephone: 020 7679 9319

Email: v.ratti.11@ucl.ac.uk

Thank you for taking the time to read this information sheet.

Paid Carer Consent Form

Participant Identification Number:

The care environment and clinical outcomes in adults with intellectual disabilities and challenging behaviour.

Please initial box

1. I have read the information sheet about this study and/or the project has been explained to me
2. I have had chance to ask questions and talk about this study
3. I am happy with the answers to all my questions
4. I have got enough information about this study
5. I understand that I can stop being part of this study whenever I want
I do not have to give a reason.
It will not change the help that the service-user receives
6. I agree to take part in this study
7. I understand that I am free to withdraw from the study without penalty if I so wish
and I consent to the processing of my personal information for the purposes of this
study only and that it will not be used for any other purpose. I understand that such
information will be treated as strictly confidential and handled in accordance with the
provisions of the Data Protection Act 1998

Signed _____ Date: _____

Name in Block Letters: _____

Researcher's Name: _____

Researcher's signature: _____ Date: _____

Questionnaires

The following statements refer to different ways that you can obtain information about residents, and to your perceptions of how well you know the residents that you are caring for.

Read each statement carefully and think about the extent to which you agree or disagree with it. Place your responses using the following scale as a guide.

1. Strongly Disagree
2. Somewhat Disagree
3. Somewhat Agree
4. Strongly Agree

Do not spend too much time on each item – your first reaction is usually the right one.

I read the social histories of resident care plans

Strongly Disagree

Strongly Agree

1 2 3 4

I do not have the time I need to read the social histories of the residents

Strongly Disagree

Strongly Agree

1 2 3 4

The quality of the resident social histories is poor

Strongly Disagree

Strongly Agree

1 2 3 4

I talk to family members and friends in order to learn what has been and may remain important to the resident

Strongly Disagree

Strongly Agree

1 2 3 4

I have a good understanding of the residents I am caring for

Strongly Disagree

Strongly Agree

1 2 3 4

I do not know the behaviour patterns of individual residents

Strongly Disagree

Strongly Agree

1 2 3 4

I know what the residents I care for like

Strongly Disagree

Strongly Agree

1 2 3 4

I find it hard to talk to the residents because I do not know much about them

Strongly Disagree

Strongly Agree

1

2

3

4

I do not think that care plans are based upon what residents value in life

Strongly Disagree

Strongly Agree

1

2

3

4

I plan a resident's personal care routine using the habits and routine they had at home

Strongly Disagree

Strongly Agree

1

2

3

4

I am aware of the skills that residents have and include them into my care approaches

Strongly Disagree

Strongly Agree

1

2

3

4

Favourite beverages, meals and activities are part of a resident's day

Strongly Disagree

Strongly Agree

1

2

3

4

I do not feel like I know each resident as a unique individual

Strongly Disagree

Strongly Agree

1

2

3

4

Here are some thoughts and feelings that people sometimes have about themselves as caregivers in care facilities. How much does each statement describe your thoughts and feelings about your ability to provide care at the facility you work in?

Please rate each item below based on how you *generally* feel about each one by using the following scale as a guide.

1. Very frequently
2. Frequently
3. Occasionally
4. Seldom
5. Never

Feel that you are not doing all you should in order to care for the residents that you look after

Very Frequently 1 2 3 4 5 Never

Feel rushed because of facility routines

Very Frequently 1 2 3 4 5 Never

Feel rushed because of the expectations of the other caregivers you work with

Very Frequently 1 2 3 4 5 Never

Feel that the facility you work in supports the independence of residents

Very Frequently 1 2 3 4 5 Never

Feel that the other caregivers you work with have different ideas about how care should be provided

Very Frequently 1 2 3 4 5 Never

Feel that you are able to allow the residents that you look after to make decisions for themselves

Very Frequently 1 2 3 4 5 Never

Feel that the residents have enough to do during the day

Very Frequently 1 2 3 4 5 Never

Feel that the facility you work in offers choice in activity programming

Very Frequently 1 2 3 4 5 Never

Feel that you have done things for residents when they could have done it for themselves

Very Frequently 1 2 3 4 5 Never

Feel that you have enough time to allow residents to do things for themselves

Very Frequently 1 2 3 4 5 Never

Feel that it is important that residents get to meals on time

Very Frequently 1 2 3 4 5 Never

Feel that the facility you work in makes an effort to include personal preferences into mealtimes

Very Frequently 1 2 3 4 5 Never

Feel good about the quality of care that you are able to provide at this facility

Very Frequently 1 2 3 4 5 Never

Feel that there are enough resources available to you to provide care

Very Frequently 1 2 3 4 5 Never

The following statements refer to different forms of communication between staff members and residents. Read each statement carefully and think about the extent to which you have used this care approach the in the last seven days. Place your responses using the following scale as a guide.

1. Never
2. Sometimes
3. Often
4. Always

Use humour when talking to residents

Never

Sometimes

Often

Always

Physically touch residents with their permission

Never

Sometimes

Often

Always

Talk to residents about social events that are going on within the facility

Never

Sometimes

Often

Always

Talk to residents about their personal lives

Never

Sometimes

Often

Always

Talk about my personal life with residents

Never

Sometimes

Often

Always

Talk to residents about the care they are receiving

Never

Sometimes

Often

Always

The following statements refer to different forms of communication between staff members.

Read each statement carefully and think about the extent to which you have used it in the last seven days. Place your responses using the following scale as a guide.

1. Never
2. Sometimes
3. Often
4. Always

Share personal information that I learn about residents that may help other staff members

Never *Sometimes* *Often* *Always*

Staff members tell me about physical changes in residents

Never *Sometimes* *Often* *Always*

Ask other staff what I should know before caring for a particular resident

Never *Sometimes* *Often* *Always*

Share care approaches that can help residents to do things for themselves

Never *Sometimes* *Often* *Always*

Share care approaches that can help manage the difficult behaviours of residents

Never *Sometimes* *Often* *Always*

Talk with other staff members in order to find out the meaning behind difficult resident behaviour

Never *Sometimes* *Often* *Always*

Tell my supervisors about the need to change a procedure or practice that is no longer working for resident care

Never *Sometimes* *Often* *Always*

Offer ideas for making changes within the care plans of residents

Never *Sometimes* *Often* *Always*

Play a part in the making of facility procedure and practices

Never

Sometimes

Often

Always

Exchange information about residents at shift change

Never

Sometimes

Often

Always

Supervisors consider the preferences of staff members when making decisions about resident care

Never

Sometimes

Often

Always

Please describe the focus-individual in your own words: what are they like as a person? How would you describe their character?

The following scale is a measure of **available choice** for a resident in his/her living environment.

Please indicate how often the following statements apply to the focus-participant.

- 1 = Never
- 2 = Almost Never
- 3 = Seldom
- 4 = Half the time
- 5 = Usually
- 6 = Almost
- 7 = Always

Does the client choose the time he/she wakes in the morning?

Never Always

1 2 3 4 5 6 7

Does the client choose his/her bedtime?

Never Always

1 2 3 4 5 6 7

Is the client's bedroom door locked at night?

Never Always

1 2 3 4 5 6 7

Does the client choose his/her own clothes in the morning?

Never Always

1 2 3 4 5 6 7

Does the client choose his/her roommate (if not in a private room)?

Never Always

1 2 3 4 5 6 7

Does the client choose the time he/she takes a bath/shower?

Never Always

1 2 3 4 5 6 7

Does the client choose the time he/she brushes his/her teeth?

Never Always

1 2 3 4 5 6 7

Does the client have a choice at mealtimes (e.g., ham vs. steak)?

Never Always

1 2 3 4 5 6 7

Does the client have a choice as to when he/she eats (e.g., 6:00 or 6.30)?

Never Always

1 2 3 4 5 6 7

Does the client choose his/her own activities during the day?

Never Always

1 2 3 4 5 6 7

For group activities, does the client choose whether or not he/she participates?

Never Always

1 2 3 4 5 6 7

May the client take walks outside by himself/herself?

Never Always

1 2 3 4 5 6 7

Is the client allowed to be in his/her bedroom alone during the day/evening?

Never Always

1 2 3 4 5 6 7

Is the client allowed to move around the building/home as he/she chooses?

Never Always

1 2 3 4 5 6 7

Does the client have a choice as to whether he/she has visitors?

Never Always

1 2 3 4 5 6 7

Does the client participate in the preparation of meals?

Never Always

1 2 3 4 5 6 7

Does the client participate in the clean-up after meals?

Never Always

1 2 3 4 5 6 7

Does the client participate in doing his/her laundry?

Never Always

1 2 3 4 5 6 7

Is the client responsible for all or part of the clean-up of his/her bedroom?

Never Always

1 2 3 4 5 6 7

Does the client choose whether he/she will receive therapy services (e.g. speech, language, occupational, music)?

Never Always

1 2 3 4 5 6 7

Does the client choose which television program he/she would like to watch?

Never Always

1 2 3 4 5 6 7

Does the client choose to which radio program he/she would like to listen?

Never Always

1 2 3 4 5 6 7

Does the client choose which activities he/she will participate in during the weekend?

Never

Always

1 2 3 4 5 6 7

Does the client choose which type of style of adaptive equipment or prosthetic device he/she utilises (e.g. wheelchair, braces)?

Never

Always

1 2 3 4 5 6 7

Please indicate your level of agreement with the following statements

The life history of the residents is formally used in care plans we use

Strongly Disagree 1 2 3 4 Strongly Agree

The environment supports residents to express their personal identity

Strongly Disagree 1 2 3 4 Strongly Agree

Residents are offered the opportunity to be involved in individualised everyday activities

Strongly Disagree 1 2 3 4 Strongly Agree

It is important to know the life histories of people with learning disabilities

Strongly Disagree 1 2 3 4 Strongly Agree

People with learning disabilities are as different from each other as any other group of people who share a disease category

Strongly Disagree 1 2 3 4 Strongly Agree

Challenging behaviours are inevitable in people with learning disabilities

Strongly Disagree 1 2 3 4 Strongly Agree

There is a homely feel to the place

Strongly Disagree 1 2 3 4 Strongly Agree

We often discuss how to give person-centred care (between staff)

Strongly Disagree 1 2 3 4 Strongly Agree

There is a pleasant atmosphere

Strongly Disagree Strongly Agree
1 2 3 4

Residents are able to access outside space as they wish

Strongly Disagree Strongly Agree
1 2 3 4

I feel supported by the organisation I work in

Strongly Disagree Strongly Agree
1 2 3 4

Social participation is important for people with learning disabilities

Strongly Disagree Strongly Agree
1 2 3 4

Learning disabilities reduce the experience of pain

Strongly Disagree Strongly Agree
1 2 3 4

We are free to alter work routines based on residents' preferences

Strongly Disagree Strongly Agree
1 2 3 4

It is necessary to hurry residents to accomplish all that has to be done

Strongly Disagree Strongly Agree
1 2 3 4

Residents have a variety of foods to choose from

Strongly Disagree Strongly Agree
1 2 3 4

In learning disabilities the body is there but the person is gone

Strongly Disagree Strongly Agree
1 2 3 4

Residents can wake up and start the day whenever they prefer

Strongly Disagree 1 2 3 4 Strongly Agree

We have formal team meetings to discuss residents' care

Strongly Disagree 1 2 3 4 Strongly Agree

The environment supports personal choice

Strongly Disagree 1 2 3 4 Strongly Agree

This organisation prevents me from providing person-centred care

Strongly Disagree 1 2 3 4 Strongly Agree

People with learning disabilities should be allowed to form sexual relationships

Strongly Disagree 1 2 3 4 Strongly Agree

Labels (e.g. wanderer, screamer) are used here to describe individuals

Strongly Disagree 1 2 3 4 Strongly Agree

People with learning disabilities have meaningful relationships

Strongly Disagree 1 2 3 4 Strongly Agree

I simply do not have the time to provide person-centred care

Strongly Disagree 1 2 3 4 Strongly Agree

Assessments of residents' needs is undertaken on a daily basis

Strongly Disagree 1 2 3 4 Strongly Agree

DEBRIEF

Person-Centred support, Choice and Challenging Behaviour in Adults with Intellectual Disabilities: the impact of the care environment on clinical outcomes, an exploratory study

Thank you for taking part in this research!

The aim of the study is to investigate whether there is a relationship between Person-Centred approaches to care and challenging behaviour in people with intellectual disabilities.

Person-Centred care has been advocated as best practice in social care and has been often recognised as the gold-standard of care.

Since challenging behaviour in people with intellectual disabilities is thought to be product of an interaction between the individual and the environment, the aim of the study is to investigate whether there are certain aspects of the care environment which make challenging behaviour less likely to occur.

The study asked questions regarding how well carers know the focus-individual, how much opportunity for independence and autonomy service-users have, how effective communication between members of staff is with, and regarding the individual in question, and how much opportunities for choice service-users are given in their everyday life.

I would like to investigate whether any of these factors have a direct relationship with the occurrence of challenging behaviour in people with intellectual disabilities and if providing care in a person-centred manner makes it less likely that challenging behaviour will occur.

If you have any questions about any of the issues raised in any of the surveys, or you feel like you would like to talk to a professional about your own experience in these areas, please feel free to contact investigator whose contact details are given below.

Victoria Ratti

Research Assistant PBS Study

Division of Psychiatry

6th Floor, Maple House,

149 Tottenham Court Road,

London W1T 7NF.

Email: v.ratti.11@ucl.ac.uk

Tel: +44 (0)20 7679 9319

Web: www.ucl.ac.uk/positive-behaviour-support

Twitter: <https://twitter.com/PBSstudy>

B3. Non-respondent carers' demographics

Age (Mean, SD)	43.26 (12.32)
Males N (%)	4 (18.2)
Education N (%)	
Degree/Higher Education	7 (31.8)
O/A-levels*	8 (36.4)
GCSE**	6 (27.3)
Other/Missing	1 (4.5)
Years experience working with people with ID (Mean, SD)	9.16 (6.58)
Years acquaintance with service-user (Mean, ID)	4.8 (4.8)

*Ordinary/Advanced level of the General Certificate of Education awarded in England, Wales and Northern Ireland, typically required for admissions to college/university

**General Certificate of Secondary Education (an examination set especially for secondary-school pupils of about age 16 in England, Wales, and Northern Ireland).

B4. RCAS Factor loadings pattern matrix of EFA with non-loading items omitted

Item	Factor		Communality
	1	2	
Does the client choose the time he/she brushes his/her teeth?	0.95	-0.16	0.82
Does the client choose the time he/she takes a bath/shower?	0.89	-0.14	0.77
Does the client choose the time he/she wakes up in the morning?	0.72	-0.21	0.57
Does the client choose his/her own activities during the day?	0.69	-0.01	0.75
Does the client choose his/ her bedtime?	0.69	-0.01	0.61
Does the client choose his/her own clothes in the morning?	0.67	0.18	0.70
Does the client choose which activities he/she will participate in during the weekend?	0.64	0.28	0.70
For group activities, does the client choose whether or not he/she participates?	0.63	0.04	0.56
Does the client have a choice as to whether h/she has visitors?	0.61	0.01	0.52
Does the client choose which TV program he/she would like to watch?	0.61	0.24	0.81
Does the client have a choice as to when he/she eats?	0.60	0.11	0.56
Does the client have a choice at mealtimes?	0.59	0.23	0.56
Does the client choose which radio program he/she would like to listen to?	0.58	0.32	0.83
Does the client participate in doing his/her laundry?	-0.02	0.77	0.67
Does the client participate in the clean up after meals?	-0.02	0.76	0.57
Is the client responsible for the clean-up of his/her bedroom?	0.08	0.68	0.59
Does the client participate in the preparation of meals?	0.07	0.45	0.25
Does the client choose which type of adaptive equipment or prosthetic device to utilise?	0.36	0.42	0.69

B5. RCAS Tests of normality and homogeneity of variance

Shapiro Wilk test of normality

Factor 1. (S-W=0.794, $df=108$, $p<.001$)

Factor 2. (S-W=0.942, $df= 108$, $p<.001$)

Levene's test of homogeneity of variance

Residential settings

Factor 1. ($F(2,105)=3.403$, $p=0.06$)

Factor 2. ($F(2,105)=0.653$, $p=0.523$)

Level of ID

Factor 1. ($F(2,105)=9.15$, $p<0.001$)

Factor 2. ($F(2,105)=0.258$, $p=0.773$)

Appendix C (Chapter 4)

C1. Positive Behaviour Support Study measures

Participant Demographics

To be completed by the service-user or carer during the interview

What is your date of birth?

(DD) ____ / ____ / ____
 (MM) (YYYY)

What is your gender?

Male Female

How would you describe your ethnicity?

<input type="checkbox"/>	White – British	<input type="checkbox"/>	Asian or Asian British – Pakistani
<input type="checkbox"/>	White – Irish	<input type="checkbox"/>	Asian or Asian British – Any other Asian background
<input type="checkbox"/>	White – Any other White background	<input type="checkbox"/>	Black or Black British – Caribbean
<input type="checkbox"/>	Mixed – White & Black Caribbean	<input type="checkbox"/>	Black or Black British – African
<input type="checkbox"/>	Mixed – White & Black African	<input type="checkbox"/>	Black or Black British – Any other Black background
<input type="checkbox"/>	Mixed – White & Asian	<input type="checkbox"/>	Other Ethnic Groups – Chinese
<input type="checkbox"/>	Mixed – Any other Mixed background	<input type="checkbox"/>	Other Ethnic Groups – Any other Ethnic group
<input type="checkbox"/>	Asian or Asian British – Indian	<input type="checkbox"/>	Not stated

What is your current living situation?

- | | |
|--|--|
| <input type="checkbox"/> Living alone (+/- children) | <input type="checkbox"/> Living with parents |
| <input type="checkbox"/> Living with husband/wife (+/- children) | <input type="checkbox"/> Living with other relatives |
| <input type="checkbox"/> Living together as a couple | <input type="checkbox"/> Living with others |

What is your current usual/normal accommodation?

<input type="checkbox"/>	Family home	<input type="checkbox"/>	Residential, 24-hour staffed
<input type="checkbox"/>	Owned by person with LD	<input type="checkbox"/>	Supported living, individual single tenancy, 24-hour staffed
<input type="checkbox"/>	Flat/house rented from local authority or housing association	<input type="checkbox"/>	Supported living, group living, 24-hour staffed
<input type="checkbox"/>	Tenancy in name	<input type="checkbox"/>	Supported living, individual single tenancy, not 24-hour staffed
<input type="checkbox"/>	Sheltered accommodation	<input type="checkbox"/>	Supported living, group living, not 24-hour staffed

How long have you been living in... _____ months

(If less than 6 months)

Where have you lived before?

How many rooms are in this accommodation?

How many of these rooms are bedrooms?

How many adults live there? (over age of 18)

No. of adults

How many children live there? (under age of 18)

No. of children

Level of intellectual disability

- Mild Moderate Severe Don't know

Do you have any physical health problems?

No

Yes *(please select all that apply)*

Mobility problems

Sensory problems

Epilepsy

Incontinence

Other – please specify _____

Aberrant Behaviour Checklist (ABC)

To be completed by either family or paid carer during the interview

Relationship to client (check):

- Paid carer
- Family carer
- Teacher
- Trainer / Supervisor
- Other – please specify _____

Where was the client observed?

- Home
 - School
 - Residential Unit
 - Workshop
 - Other – please specify _____
-

Please rate this client's behaviour for the last four weeks. For each item, decide whether the behaviour is a problem and circle the appropriate number:

0 = not at all a problem 1 = the behaviour is a problem but slight in degree 2 = the problem is moderately serious 3 = the problem is severe in degree

When judging the client's behaviour, please keep the following points in mind:

- a) Take relative *frequency* into account for each behaviour. For example, if the client averages more temper outbursts than most other clients you know or most others in his/her class, it is probably moderately serious (2) or severe (3), even if these occur only once or twice a week. Other behaviours, such as noncompliance, would probably have to occur more frequently to merit an extreme rating.
- b) If you have access to this information, consider the experiences of other care provider with this client. If the client has problems with others but not with you, try to take the whole picture into account.
- c) Try to consider whether a given behaviour interferes with his/her *development, functioning or relationships*. For example, body rocking or social withdrawal may not disrupt other children or adults, but it almost certainly hinders individual development or functioning.

Do not spend too much time on each item – your first reaction is usually the right one.

- | | | | | |
|--|---|---|---|---|
| 1. Excessively active at home, school, work, or elsewhere | 0 | 1 | 2 | 3 |
| 2. Injures self on purpose | 0 | 1 | 2 | 3 |
| 3. Listless, sluggish, inactive | 0 | 1 | 2 | 3 |
| 4. Aggressive to other children or adults (verbally or physically) | 0 | 1 | 2 | 3 |

5. Seeks isolation from others	0	1	2	3
6. Meaningless, recurring body movements	0	1	2	3
7. Boisterous (inappropriately noisy and rough)	0	1	2	3
8. Screams inappropriately	0	1	2	3
9. Talks excessively	0	1	2	3
10. Temper tantrums/outbursts	0	1	2	3
11. Stereotyped behaviour; abnormal, repetitive movements	0	1	2	3
12. Preoccupied; stares into space	0	1	2	3
13. Impulsive (acts without thinking)	0	1	2	3
14. Irritable and whiny	0	1	2	3
15. Restless, unable to sit still	0	1	2	3
16. Withdrawn; prefers solitary activities	0	1	2	3
17. Odd, bizarre in behaviour	0	1	2	3
18. Disobedient; difficult to control	0	1	2	3
19. Yells at inappropriate times	0	1	2	3
20. Fixed facial expression ; lacks emotional responsiveness	0	1	2	3
21. Disturbs others	0	1	2	3
22. Repetitive speech	0	1	2	3
23. Repetitive speech	0	1	2	3
24. Does nothing but sit and watch others	0	1	2	3
25. Uncooperative	0	1	2	3
26. Depressed mood	0	1	2	3
27. Resists any form of physical contact	0	1	2	3
28. Moves or rolls head back and forth repetitively	0	1	2	3
29. Does not pay attention to instructions	0	1	2	3
30. Demands must be met immediately	0	1	2	3
31. Isolates himself / herself from other children or adults	0	1	2	3
32. Disrupts group activities	0	1	2	3
33. Sits or stands in one position for a long time	0	1	2	3
34. Talks to self loudly	0	1	2	3
35. Cries over minor annoyances and hurts	0	1	2	3
36. Repetitive hand, body, or head movements	0	1	2	3
37. Mood changes quickly	0	1	2	3
38. Unresponsive to structured activities (does not react)	0	1	2	3
39. Does not stay in seat (e.g. during lesson or training periods, meals, etc.)	0	1	2	3
40. Will not sit still for any length of time	0	1	2	3
41. Cries and screams inappropriately	0	1	2	3
42. Prefers to be alone	0	1	2	3
43. Does not try to communicate by words or gestures	0	1	2	3
44. Easily distractible	0	1	2	3
45. Waves or shakes the extremities repeatedly	0	1	2	3
46. Repeats a word or phrase over and over	0	1	2	3
47. Stamps feet or bangs objects or slams doors	0	1	2	3
48. Constantly runs or jumps around the room	0	1	2	3
49. Rocks body back and forth repeatedly	0	1	2	3
50. Deliberately hurts himself / herself	0	1	2	3
51. Pays no attention when spoken to	0	1	2	3
52. Does physical violence to self	0	1	2	3
53. Inactive, never moves spontaneously	0	1	2	3
54. Tends to be excessively active	0	1	2	3
55. Responds negatively to affection	0	1	2	3
56. Deliberately ignores directions	0	1	2	3
57. Has temper outbursts or tantrums when he/she does not get own way	0	1	2	3
58. Shows few social reactions to others	0	1	2	3

Short Form Adaptive Behaviour Scale (SABS)

This Scale consists of a number of statements that describe some of the ways people act in different situation.

When completing the Scale, please observe the following general rules:

1. Items that specify “with help” or “with assistance” for completion of the task refer to direct physical assistance.
2. Give credit for an item even if verbal prompting or reminding is needed to complete the task, unless the item definitely states “without prompting” or “without reminder”.

Some items may deal with behaviours that are clearly against local regulations (e.g. use of the telephone) or behaviours that are not possible for a person to perform because the opportunity does not exist (e.g. eating in restaurants is not possible for someone who is bedridden). In these instances, you must still complete your rating. Give persons credit for the item if you feel certain that they could and would perform the behaviour without additional training if they were given the opportunity to do so.

There are two types of items in the Scale. The first requires that you **select only the highest level of behaviours exhibited by the person being rated.** For example:

ITEM 2	Eating in public <i>(Circle the highest level)</i>	
	Orders complete meals in restaurants	3
	Orders simple meals, like hamburgers or hot dogs	<u>2</u>
	Orders simple items, e.g. soft drinks, ice cream, donuts, at soda fountain or canteen	1
	Does not order food in public eating places	0
		<u>2</u>

Notice that the statements are arranged in order of difficulty. **Circle the number of the one statement that best describes the most difficult or highest level task the person can usually manage** and then **record the number in the adjacent box.** In this example, the individual being observed can order simple meals like hamburgers or hotdogs (2) but cannot order a complete dinner (3). Therefore, the “2” is circled and recorded in the box.

The second type of item asks you to read each statement and **circle the number corresponding to a “Yes” or “No” response.** There may be instances when a statement appears with the item because certain items do not apply to the individual being rated. In those cases, follow the instructions by placing a check mark in the blank provided and circling the values associated with “Yes” or “No” as instructed.

For example:

ITEM 13	Care of clothing <i>(Circle all answers)</i>		
		Yes	N
	Wipes and cleans shoes when needed	<u>0</u>	1
	Puts clothes in drawer, chest or cupboard	<u>0</u>	1
	Hangs up clothes without prompting	0	<u>1</u>
	Calls attention to missing buttons and holes and/or repairs clothing	0	<u>1</u>
			<u>2</u>

For other items of the second type, positive ratings (i.e. 0) appear under “Yes”, with negative ratings (i.e. 1) appearing under “No”. In this example, the ratee “wipes and cleans shoes when needed” and “puts clothes in drawer, chest of cupboard”. Thus the 0s are circled (indicating a “Yes” response) for these

behaviours and the 1s (indicating a “No” response” are circled for all others. The points are summed and the “2” is recorded in the box.

Domain 1. Independent Functioning		
A. Eating		
1. Use of table Utensils		
<i>(Circle highest level)</i>		
Uses knife for cutting or spreading	6	
Feeds self neatly with spoon and fork (or appropriate alternative utensil, e.g. chopsticks)	5	
Feeds self, causing considerable spilling with spoon and fork (or appropriate alternate utensil, e.g. chopsticks)	4	
Feeds self with spoon – neatly	3	
Feeds self with spoon – considerable spilling	2	
Feeds self with fingers	1	
Does not feed self or must be fed	0	
2. Eating in public		
<i>(Circle the highest level)</i>		
Orders complete meals in restaurants	3	
Orders simple meals, like hamburgers or hot dogs	2	
Orders simple items, e.g. soft drinks, ice cream, donuts, at soda fountain or canteen	1	
Does not order food in public eating places	0	
B. Toilet Use		
1. Self-care at toilet		
<i>(Circle all answers)</i>	Yes	No
Lowers pants at toilet without help	1	0
Sits on toilet seat without help	1	0
Uses toilet tissue appropriately	1	0
Flushes toilet after use	1	0
Puts on clothes without help	1	0
Washes hands without help	1	0
C. Cleanliness		
1. Bathing		
<i>(Circle the highest level)</i>		
Prepares and completes bathing unaided	6	
Washes and dries self completely without prompting or helping	5	
Washes and dries reasonably well with prompting	4	
Washes and dries self with help	3	
Attempts to soap and wash self	2	
Cooperates when being washed and dried by others	1	
Makes no attempt to wash or dry self	0	
2. Care of clothing		
<i>(Circle all answers)</i>	Yes	No
Wipes and cleans shoes when needed	1	0
Puts clothes in drawer, chest or cupboard	1	0
Hangs up clothes without prompting	1	0

Calls attention to missing buttons and holes and/or repairs clothing	1	0
--	---	---

D. Dressing and undressing

1. Dressing

(Circle highest level)

Completely dresses self	5
Dresses self with verbal prompting only	4
Dresses self by pulling or putting on all clothes with verbal prompting and by fastening (zipping, buttoning, snapping, Velcro) them with help	3
Dresses self with help in pulling or putting on mist clothes and fastening them	2
Cooperates when being dressed by extending arms and legs	1
Must be dressed completely	0

2. Shoes

(Circle all answers)

	Yes	No
Puts on shoes correctly without assistance	1	0
Ties shoes correctly without assistance	1	0
Unties shoes correctly without assistance	1	0
Removes shoes without assistance	1	0
Attaches or detaches Velcro on shoes	1	0

E. Other independent functioning

1. Miscellaneous Independent Functioning

Yes No

(Circle all answers)

Has ordinary control of appetite, eats moderately	1	0
Knows postage rates, buys stamps from post office	1	0
Looks after personal health, e.g. changes wet clothing	1	0
Deals with simple injuries, e.g. cuts, burns	1	0
Knows how and where to obtain a doctor's or dentist's help	1	0
Knows own address	1	0

2. Safety at Residential Facility or Home

(Circle the highest level)

Asks whether an unfamiliar object is safe to touch or consume	1
Is careful about danger of electrical outlets and sockets	2
Is careful about danger of hot foods and beverages, or hot dishes or pans	3
Is not careful about possible danger	4

Domain 2. Physical Development

1. Motor Development

(Circle all answers)

Yes No

Walks alone	1	0
Walks up and down stairs alone	1	0
Walks down stairs by alternating feet	1	0
Runs without often falling	1	0
Hops, skips or jumps	1	0

Domain 3. Economic Activity

1. Money Handling

(Circle highest level)

Takes complete care of own money	4
Makes change correctly but does not use banking facilities	3
Adds coins of various denominations, up to £1	2
Uses money but does not make change correctly	1
Does not use money	0
2. Purchasing	
<i>Circle highest level)</i>	
Buys own clothing	5
Buys own clothing accessories	4
Makes minor purchases without help (candy, soft drinks, etc.)	3
Does shopping with slight supervision	2
Does shopping with close supervision	1
Does no shopping	0
Domain 4. Language Development	
1. Sentences	
<i>(Circle highest level)</i>	
Sometimes uses complex sentences containing “because”, “but”, etc.	3
Asks questions using words such as “why”, “how”, “what”, etc.	2
Speaks in simple sentences	1
Speaks in primitive phrases only or is nonverbal	0
2. Comprehension of social instructions	
<i>(Circle the highest level)</i>	
Understands complex instructions involving a decision, “if ____, do this, but if not, do ____.”	4
Understands instructions involving a series of steps, e.g. “First do ____, then do ____.”	3
Answers simple questions such as “What is your name?” or “What are you doing?”	2
Responds correctly to simple phrases, e.g. “stop”, “sit down”, “come here “	1
Is unable to understand even very simple verbal communications	0
Domain 5. Numbers and Time	
<i>(Circle all answers)</i>	
Performs division and multiplication	6
Does simple addition and subtraction	5
Counts ten or more objects	4
Mechanically counts to ten	3
Counts two objects by saying “one... two”	2
Discriminates between “one” and “many” or “a lot”	1
Has no understanding of numbers	0
Domain 6. Domestic Activity	
1. Food preparation	
<i>(Circle the highest level)</i>	
Can use microwave correctly to prepare a meal	4
Prepares an adequate complete meal (may use canned or frozen food)	3
Mixes and cooks simple food, e.g. fried eggs, makes pancakes, cooks TV dinners, etc.	2
Prepares simple food requiring no mixing or cooking, e.g. sandwiches, cold cereal, etc.	1
Does not prepare food at all	0
2. General domestic activity	

<i>(Circle all answers)</i>	Yes	No
Washes dishes well	1	0
Makes bed neatly	1	0
Helps with household chores	1	0
Does household chores routinely	1	0
Can load and use dishwasher correctly	1	0
Can use small, electric kitchen appliances correctly	1	0
Domain 8. Self-Direction		
1. Passivity		
<i>(Circle all answers)</i>	Yes	No
Needs constant encouragement to complete task	1	0
Has to be made to do things	1	0
Has no ambition	1	0
Seems to have no interest in things	1	0
Finishes task last because of wasted time	1	0
Is unnecessarily dependent on others for help	1	0
Movement is slow and sluggish	1	0
2. Persistence		
<i>(Circle all answers)</i>	Yes	No
Cannot organize task	1	0
Becomes easily discouraged	1	0
Fails to carry out tasks	1	0
Jumps from one activity to another	1	0
Needs constant encouragement to complete task	1	0
3. Leisure Time		
<i>(Circle highest level)</i>		
Organize leisure time activities on a fairly complex level, e.g. going on a fishing trip, arranging to play billiards, scheduling time to do computer games, etc.	4	
Has active interest in hobby, e.g. painting, embroidery, collecting stamps, coins, baseball cards, etc.	3	
Participates in organized leisure time activity when arranged from him or her	2	
Engages in leisure activity on a simple level, e.g. watching TV, listening to the radio, etc.	1	
Is unable to arrange leisure time activity, even of the simplest nature	0	
Domain 9. Responsibility		
1. General Responsibility		
<i>(Circle highest level)</i>		
Very conscientious and assumes much responsibility – makes a special effort; assigned activities are always performed	3	
Usually dependable – makes an effort to carry out responsibilities; one can be reasonably certain that assigned activities will be performed	2	
Unreliable – makes little effort to carry out responsibilities; one is uncertain that the assigned activities will be performed	1	
Not given responsibilities; is unable to carry out responsibilities at all	0	
2. Personal Responsibility		
<i>(Circle all answers)</i>	Yes	No
Usually maintains self-control	1	0
Understands concept of being on time	1	0
Seeks and accepts help on instructions	1	0
Reports (to teachers, supervisor, etc.) if there is a problem	1	0

Domain 10. Socialisation

1. Consideration for others

(Circle all answers)

Yes No

Shows interest in the affairs of others

1 0

Takes care of others' belongings

1 0

Directs or manages the affairs of others when needed

1 0

Shows consideration for others' feelings

1 0

2. Awareness of others

(Circle all answers)

Yes No

Recognizes own family

1 0

Recognizes people other than family

1 0

Has information about others, e.g. job, address, relation to self

1 0

Knows the names of people close to him or her, e.g. classmates, neighbours

1 0

Knows the names of people not regularly encountered

1 0

Caregiving Difficulty Scale (CDS-ID)

To be completed by the paid carer during the interview

What is your date of birth?

____ / ____ / ____
(DD) (MM) (YYYY)

What is your gender?

Male Female

How long have you been caring for people with learning disabilities?
_____ months

What is your highest level of educational qualification?

Please circle to what extent each item represented a difficulty for you during the past month. Please complete all items.

0 = Has never occurred / Behaviour is not a difficulty
1 = Sometimes a difficulty
2 = Frequently a difficulty
3 = A great deal of difficulty

Factor 1 – Day to Day Care Issues

1. Assisting with care-recipient's toileting	0	1	2	3
2. Transporting care-recipient	0	1	2	3
3. Bathing care-recipient	0	1	2	3
4. Care-recipient yelling swearing	0	1	2	3
5. Care-recipient not cooperating	0	1	2	3
6. Assisting care-recipient with exercises/therapy	0	1	2	3
7. Doing care-recipient's laundry	0	1	2	3
8. Care-recipient leaving tasks uncompleted	0	1	2	3
9. Care-recipient being confused, not making sense	0	1	2	3
10. Lifting or transferring care-recipient	0	1	2	3
11. Care-recipient frowning/scowling	0	1	2	3
12. Care-recipient living in past	0	1	2	3

13. Helping care-recipient eat	0	1	2	3
14. Picking up after care-recipient	0	1	2	3
15. Being in care-recipient's presence	0	1	2	3
16. Care-recipient talking about/seeing things that are not real	0	1	2	3
17. Dressing care recipient	0	1	2	3
18. Care-recipient not recognizing familiar people	0	1	2	3
19. Giving medications to care-recipient	0	1	2	3
20. Preparing meals for care-recipient	0	1	2	3
21. Care-recipient wandering off	0	1	2	3
22. Care-recipient's agitation	0	1	2	3
23. Assisting care-recipient with health aids (e.g., dentures)	0	1	2	3
24. Care-recipient requiring day supervision	0	1	2	3
25. Leaving care-recipient with others	0	1	2	3
26. Care-recipient hiding things	0	1	2	3
27. Care-recipient requiring night supervision	0	1	2	3

Factor 2 – Care Challenges

28. Conflicts between care-recipient and housemates/peers	0	1	2	3
29. Conflicts between care-recipient and staff	0	1	2	3
30. Housemates/peers not showing understanding about Care-recipient	0	1	2	3
31. Not having additional resources/staff to address dementia needs	0	1	2	3
32. Design of the home	0	1	2	3
33. Lack of adaptive equipment	0	1	2	3
34. Attending to medical care needs as dementia progresses	0	1	2	3
35. Not having enough knowledge and training in caring for persons with dementia	0	1	2	3
36. Conflicts with other staff about appropriate care and level of dementia needs	0	1	2	3

Factor 3 - Family Concerns

37. Family not showing understanding about care-recipient	0	1	2	3
---	---	---	---	---

38. Not receiving caregiving help from family and guardian 0 1 2 3

Guernsey Community Participation and Leisure Assessment (GCPLAS)

Overleaf is a list of potential activities or contacts clients may have access to

For each activity, please look at the separate list of definitions.

Please indicate by a number in the column labelled **FREQUENCY** how often they do this:

NUMBER	DEFINITION
0	Never
1	Very occasionally
2	3 monthly or more frequently
3	Monthly "
4	Weekly "
5	Daily "

Please indicate by a number in the column labelled **SUPPORT** whether they usually are:

NUMBER	DEFINITION	NOTES
1	Supervised	Supervised = Either The onus of choice and control lies with carer, Or A major part of the carer's attention is concerned with vigilance for the individual, Or A combination of the two
2	With carers, but not supervised	Carer = relative or paid member of staff
3	Unaccompanied	-
4	With a peer group	Peer Group = includes all those who do not fulfil criteria of carer. If carer present rate as 1 or 2.

For those activities that are seasonal, e.g. beach, try to reflect how often the person would do this at the appropriate time of year.

ACTIVITY	FREQUENCY	SUPPORT
----------	-----------	---------

A. SERVICES

Doctor (GP)		
Dentist		
Hospital		
Police		

B. PUBLIC TRANSPORT

Bus		
Train		
Taxi		
Boat		
Aeroplane		

C. INDOOR LEISURE

Craft		
Games		
T.V.		
Videos/DVDs		
Music (Listen)		
Music (Play)		
Pets		

D. LEISURE, SPORT & RECREATION

Fair/Fete/Festival		
Museum/Art Gallery		
Sport (Participation)		
Sport (Spectator)		
Exercise/Aerobic Class		
Cycling		
Cinema		
Theatre		
Concert		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily

1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group

ACTIVITY	FREQUENCY	SUPPORT
Park		
Beach		
Walking		
Holiday		
Swimming		
Sailing		
DIY		
Gardening		

E. SOCIAL

Disco		
Pub		
Party		
Restaurant/Cafe		
Friend's House		
Neighbour's Home		
Social Club (Integrated)		
Social Club (Segregated)		

F. FACILITIES/AMENITIES

Local Shop		
High Street Store		
Post Office		
Hairdresser		
Supermarket		
Chemist		
Bank/Building Society		
Place of Worship		
Large Retail Outlet		
Jumble/Car Boot Sale		
Library		
Adult Education		

0 = Never, 1 = Very occasionally, 2 = Quarterly or more frequently, 3 = Monthly, 4 = Weekly, 5 = Daily
 1 = Supervised, 2 = Accompanied, 3 = Alone, 4 = Peer group

SCORING

1	<u>Range</u>	<input type="text"/>	Add up the number of regular activities (a score of 2 or more in the Frequency column).
2	<u>'Busy'</u>	<input type="text"/>	Add up the number of very frequent activities (a score of 4 or 5 in the Frequency column).
3	<u>Independence</u>		
	Supervised	<input type="text"/>	Add the number of activities scoring 1 in the Support column
	Accompanied	<input type="text"/>	Add the number of 2s in the Support column
	Solitary activity	<input type="text"/>	Add the number of 3s in the Support column
	Peer	<input type="text"/>	Add the number of 4s in the Support column

SCORE ANALYSIS

	Category	Range	Busy	Supervised	Accompanied	Solitary	Peer
A	Services						
B	Public transport						
C	Indoor leisure						
D	Leisure, sport & recreation						
E	Social						
F	Facilities/ amenities						

TOTAL							
--------------	--	--	--	--	--	--	--

'Community' (=Total minus C)							
'Leisure' (=C+D+E)							

C2.UCL Ethics Committee letter of approval

Professor
Angela
Hassiotis
Division of
Psychiatry

UCL

14 January 2015

Dear Professor Hassiotis

Notification of Ethical Approval

Project ID 3847/002: Person-centred care, choice and challenging behaviour in adults with intellectual disabilities: the impact of the care environment on clinical outcomes. An exploratory study

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee that I have approved by your study for the duration of the project i.e. **until January 2017**.

Approval is subject to the following conditions:

1. You must seek Chair's approval for proposed amendments to the research for which this approval has been given. Ethical approval is specific to this project and must not be treated as applicable to research of a similar nature. Each research project is reviewed separately and if there are significant changes to the research protocol you should seek confirmation of continued ethical approval by completing the 'Amendment Approval Request Form': <http://ethics.grad.ucl.ac.uk/responsibilities.php>
2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. Both non-serious and serious adverse events must be reported.

Reporting Non-Serious Adverse Events

For non-serious adverse events you will need to inform Helen Dougal, Ethics Committee Administrator (ethics@ucl.ac.uk), within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair of the Ethics Committee will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

Reporting Serious Adverse Events

The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.

On completion of the research you must submit a brief report (a maximum of two sides of A4) of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

With best wishes for the research. Yours sincerely

A handwritten signature in black ink, appearing to read 'J Foreman', with a stylized flourish at the end.

Professor John Foreman

Chair of the UCL Research Ethics Committee

cc: Victoria Ratti, Applicant

Academic Service, 2 Taviton Street,

University College London Gower Street London WC1E 6BT Tel: +44 (0)20 3108 4312

[Email: ethics@ucl.ac.uk](mailto:ethics@ucl.ac.uk)

<http://ethics.grad.ucl.ac.uk/>

C3. Distribution of person-centred support and choice measures

Figure C3.1. Individualised Care total distribution

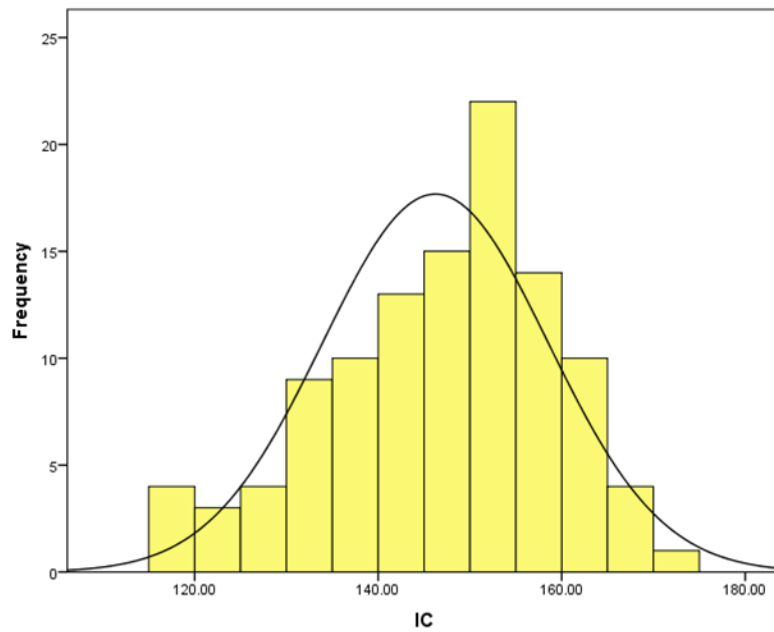


Figure C3.2. Tool for Understanding Residents' Needs as Individual Persons total distribution

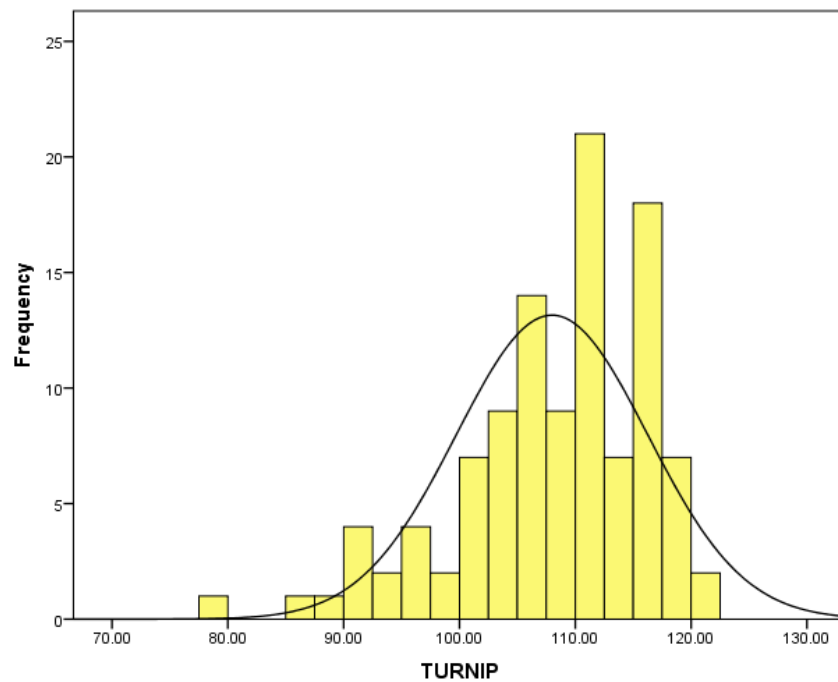
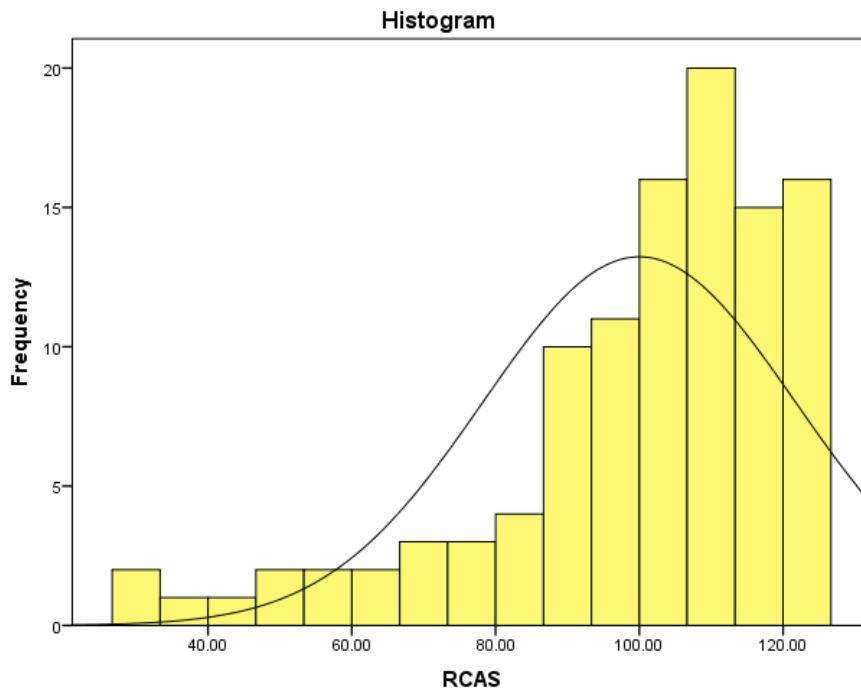


Figure C3.3. RCAS total distribution



C4. Person-centred support and community participation (controlling for adaptive behaviour)

Community Participation (Range)	B	SE B	β	p
Constant	5.84	1.47		.000
Adaptive Behaviour	.091	.023	.371	.000
Choice total	.147	.060	.226	.016
Community Participation (Busy)	B	SE B	β	p
Constant	-6.755	3.82		0.81
Adaptive Behaviour	.068	.014	.403	.000
IC Total	.085	.028	.259	.003
Constant	-3.90	4.59		.398
Adaptive Behaviour	.064	.015	.380	.000
TURNIP Total	.079	.042	.164	.065
Constant	1.00	1.62		.537
Adaptive Behaviour	.041	.017	.246	.017
Choice Total	.047	.018	.261	.011

C5. Residential settings characteristics and person-centred support: Suitability for parametric analyses tests

Shapiro Wilk's test of normality

Variable	S-W Statistic	df	p
IC	.967	108	.009
TURNIP	.941	108	.000
RCAS	.875	108	.000

Test of homogeneity of variance

Factor: Residential Setting

Variable	Leven Statistic	df1	df2	p
IC	.62	2	106	.121
TURNIP	.05	2	106	.943
RCAS	2.15	2	105	.121

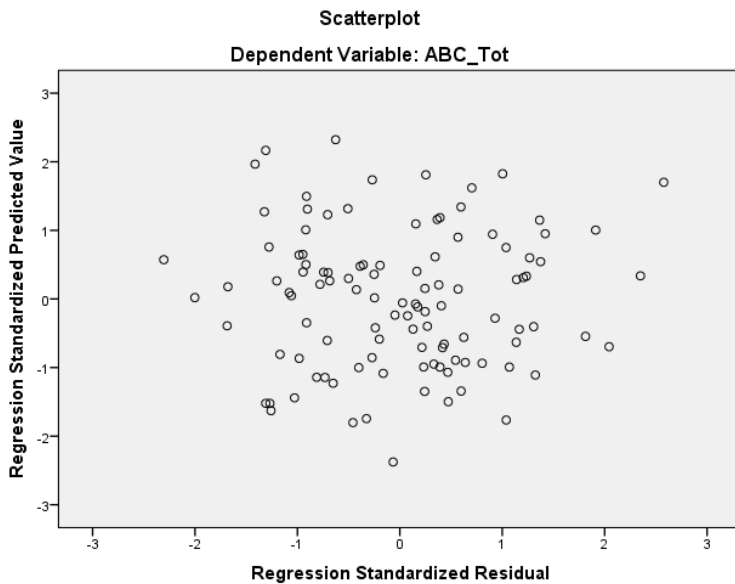
C6. Tests of General Linear Model assumptions for multiple regressions

Challenging behaviour and Individualised Care

Residuals normally distributed: Shapiro-Wilk=.989, $p=.544$

Range Variance Inflation Factor (VIF) : 1.00-1.16

Figure C6.1. IC homoscedasticity scatterplot

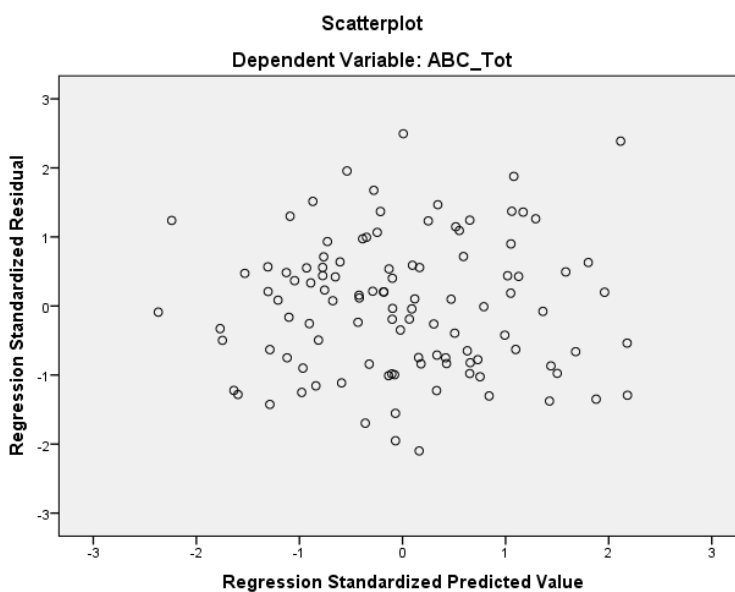


Challenging behaviour and TURNIP

Residuals normally distributed: Shapiro-Wilk = .987 $p = .379$;

VIF range: 1.03-1.16

Figure C6.2. TURNIP homoscedasticity scatterplot

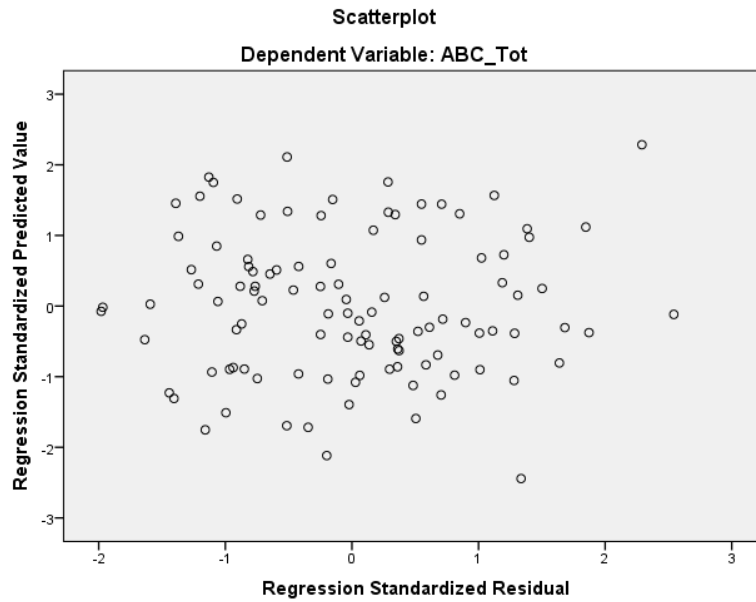


Challenging behaviour and Choice

Residuals normally distributed: Shapiro-Wilk = .987 $p = .375$;

VIF range: 1.00-1.49

Figure C6.3. Choice Homoscedasticity scatterplot



Appendix D (Chapter 5)

D1. Observations coding process

Coding System for Observations

ENGAGEMENT IN MEANINGFUL ACTIVITY (Mansell & Beadle-Brown, 2012)

Taking part in an activity that is purposeful e.g. doing something constructive with materials (washing dishes), interacting with someone, joining group activities. Activity that is likely to increase a person's independence and have control over the environment. Different from being disengaged which would literally be sitting doing nothing, standing, pacing or engaging in a purposeless activity e.g. repetitive behaviour.

ACTIVITY (Mansell & Beadle-Brown, 2012)

-Social: interacting with others (talking to, showing, sharing information, listening and paying attention to someone speaking or interacting with them)

-Non-social: any task or activity that is meaningful and that it promotes the individual's quality of life and it can include leisure, household tasks and work activities

-Unclear non-social: participation by people with profound and multiple disabilities where staff were providing hand-over-hand support to an individual to take part in activity but where it was unclear whether the person was engaged in that they were looking away at the time of the observation rather than looking at their hands or staff member

CHALLENGING BEHAVIOUR

- Self-stimulatory or repetitive (e.g. Repetitive movements, rocking, repetitive speech and repetitive manipulation of objects.)
- Self-injurious (e.g. Head-banging, scratching, pulling, eye poking, picking, grinding teeth, eating things that aren't food).
- Aggressive or destructive (e.g. Biting and scratching, hitting, pinching, grabbing, hair pulling, throwing objects, verbal abuse, screaming, shouting, spitting).

CHOICE OFFERED

Choice: "Selection of an alternative between two or more options or the expression of a self-initiated preference (Ip et al., 1994). Passive compliance with something proposed by others does not constitute choice (Stancliffe, 2001, p.92)

For verbal service-users:

- Staff offers between alternatives: e.g. Do you want to go to the cinema or swimming?
- Staff gives an option? E.g. would you like a cup of tea?

For non-verbal service-users.

- Staff uses alternative means of communication to provide choice i.e. pictures, symbols, signs or shows items to service-user e.g. staff holds up juice or water and asks which one do you want? Or presents service-user with pictures, or opens the cupboard for service-user to pick what they want to eat or wear.

AUTONOMY ENCOURAGED

Staff is promoting the individual to acquire skills aimed at improving his/her independence e.g. if assisting someone with making dinner even if the individual is only making a small contribution but staff are encouraging him/her to take part with setting the table or passing the vegetables etc. that would reflect promoting the individual's autonomy.

OFFER TO BE INVOLVED

This reflects the staff doing an activity and offering the service-user to be involved in that activity e.g. if staff member has started cooking for the individual does he/she encourage the individual to participate in that activity?

INTERACTION

Staff/resident (Felce et al., 1998):

- Assistance: assistance by staff to engage in a meaningful activity
- Praise: positive verbal, gestural or physical feedback
- Restraint: disapproval or physically preventing activity
- Processing: doing something to a person without their participation
- Other: any other form of interaction

The nature of these interactions will also be coded with codes for effective communication suggested by Oakes (2000)

- Helpful speaking – giving information/explanation
- Helpful listening- receiving information/explanation
- Positive controlling – telling a person to do something
- Negative controlling – telling a person not to do something

- Casual – all other interaction

Resident/Resident: any contact to or from another resident

Staff/Staff

-care related: staff explaining/telling another member of staff something related to service-users' care e.g. Mark needs to go to the doctor at 2pm.

-non-care related: staff talking to each other about personal matters or things unrelated to the job e.g. "have you seen the news about junior doctors/"

QUALITY OF THE INTERACTION

-Positive

-Negative

-Neutral

Judgement on the quality of the interaction will be guided by the codes set out by Oakes 2000 and by the warmth of the interaction and the tone of voice.

Helpful speaking and helpful listening will be rated as positive

Casual interactions will be judged depending on the tone of voice used e.g. if someone says "good man" that would be positive, if someone makes a statement such as "I will make tea now" that would be neutral.

Interactions will be coded as negative when someone uses a negative tone or tells someone to do or not to do something with a raised tone of voice e.g. "go to your room", "don't come here".

Examples from Dean et al. (1993)

Positive

Social interaction principally involving 'good, constructive, beneficial' conversation and companionship:

- Greetings directed to individuals
- General chat and conversation, on its own or during other social and physical care activities
- Offering choices (e.g. food, drink, nail colour)
- Serving food while saying what it is, asking if subject likes it, who made it, etc.

- Offering more food/asking if finished, only if carer waits for a response
- Verbal explanation, encouragement and comfort during other care tasks (lifting, moving, walking, bathing, etc.) that is more than necessary to carry out the task

Positive care Interactions during the appropriate delivery of physical care:

- Toileting, bathing, medication, feeding, etc. These may involve brief verbal explanations and encouragement, but only that necessary to carry out the task
No general conversation
- Keeping safe or removal from danger with explanation and reassurance

Neutral

Brief, indifferent interactions not meeting the definitions of the other categories:
Undirected 'good morning/hello/goodbye'

Negative

- Putting plates down without verbal or nonverbal contact
- Providing care, keeping safe or removing from danger, but in a restrictive manner, without explanation or reassurance: 'Don't hit X'
- Being fed too quickly 'Don't eat that, it's been on the floor'
- Being told to wait for medication treatment

Negative restrictive Interactions that oppose or resist residents' freedom of action without good reason, or which ignore resident as a person:

- Being moved without warning or explanation
- Told to do something (e.g. button dress) without discussion, explanation or help offered
- Being told can't have something (e.g. cup of tea) without good reason/explanation
- Being told not allowed to swear
- Show anger Being sworn at or physically assaulted

REACTIVITY

This will be recorded when either a service-user or a member of staff engages with the observer. These will not be counted as interactions.

D2. Active Support Measure

0 (poor, inconsistent support/performance) to 3 (good, consistent support/performance)

	0	1	2	3
Age appropriateness of activities and materials				
Real' rather than pretend or very simple activities				
Choice of activities				
Demands presented carefully				
Tasks appropriately analysed to facilitate service-user involvement				
Sufficient staff contact for service-users				
Graded assistance to ensure service-user success				
Speech matches developmental level of service-user				
Interpersonal warmth				
Differential reinforcement of adaptive behaviour				
Staff notice and respond to service-user communication				
Staff manage serious challenging behaviour well				
staff work as a coordinated team to support service-users				
Teaching is embedded in everyday activities				
Written plans in routine use				

D3. Procedure for observations outlines by Beasley et al (1993)

1. On arrival make sure the living unit staff know who you are and why you are there and tell them that, while observing, you will not usually be able to interact with service users or with them. Allow sufficient time for this before the start of the observation session, especially on the first day of observation for each new client.
2. The aim is to observe as unobtrusively as possible. Although a single observer will often take observations relatively furtively it is important that the observer is placed where they can see everything that could affect the code (e.g. if looking through a window at a client in the garden, the observer must be able to see whether, if the client speaks to another person, that person is reciprocating).
3. Generally, the observer should walk into the room to a position where they can observe the client, avoid eye contact with anyone, stand as still as possible and look at the display until it is time to observe. They should not talk to or distract anyone.
4. Wear flat, soft-soled shoes that will not sound loud on stairs or hard floors. Close doors carefully – some doors with automatic closers may shut with a loud slam. Do not handle materials, move objects or otherwise intervene in the environment unless someone's safety is directly threatened.
5. Do not go into rooms where a person might reasonably be expected to be asleep in bed, undressed, or working with a member of staff on a programme which might be disrupted by another person coming in. Generally, this means not entering toilets or bathrooms, or bedrooms at the beginning and end of the day. The observer should enter these rooms if, for example, the person is doing housework.
6. In order to help clients and staff discriminate when they can talk to observers, make it clear at the outset of the session and put the records away when you have finished. If the observer has been talking to clients or staff before the start of the session, they should make it clear to everyone that they are going to start observing. Further contacts should then be ignored (extinction of client and staff initiating to observers will be helped if the observers avoid eye contact as far as possible). At the end of the session (when no more observations are being taken) put away the records, tell everyone that observations are finished and spend a few minutes socialising.
7. If the person you are observing (or anyone else in view) seems likely to come to serious harm unless you intervene immediately, do so. You can either re-start observations later or go another day if need be.

D4. Information sheets and consent forms

Home Manager Information Sheet

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study).

I am a research assistant from the Positive Behaviour Support (PBS) study which has involved one or more carers and service users from the facility you manage. As part of my PhD project, I am exploring challenging behaviour in people with learning disabilities in relation to the care environment; some carers who helped with the PBS study have also completed some questionnaires on person-centred support. I now need to carry out additional work such as observations in order to supplement the findings from the carers' responses. I would like to invite you to consider the possibility of me carrying out observations in the home that you manage.

Before you decide whether you want to be involved I would like you to understand why I am doing the research and what it would involve for you. Please contact me if there is anything that is not clear – contact details at the end.

What is the study about?

The study is part of my PhD project which adds to the larger PBS study which one or more residents and carers in the facility you manage have already taken part in.

The aim of the observations is to explore the circumstances in which challenging behaviour is likely to occur and the characteristics of the living and care environment in which people with intellectual disabilities and challenging behaviour are currently living in.

It is important to explore whether there are certain circumstances or certain characteristics of the living environment and the care provided by staff that may act as protective factors against the occurrence of challenging behaviour.

Who can take part in this research?

I would like to observe adults with intellectual disabilities and challenging behaviour who have already taken part in the PBS study.

Do I have to help?

No. It is up to you to decide to help us with the study.

What will happen if I decide to help?

If you agree for me to carry out the observations in the participants' home, I will arrange a time to visit; this will usually be in the early evening before dinner time as previous research has found that this time of the day offers a good representation of the typical day of people with learning disabilities. However, I will be happy to negotiate another time, if there are reasons why this may be more appropriate and to avoid any possible disruption.

I will be at the participants' home for a period of approximately one hour and observe the typical environment, taking notes of the participant's behaviour, activities, interactions with other residents or staff and of the care provided by paid carers.

To minimise the impact of my presence there will be some time (10-15 minutes) before I start the observations to allow residents and staff to familiarise themselves with me and to get comfortable with me being around. When the observations begin, I will be as unobtrusive as possible, so that residents and staff will not feel influenced by my presence as the aim of the research is to observe the typical environment of the participant.

Observations will only be conducted in communal areas and if at any time residents or staff show any signs of distress due to my presence, I will stop the observations immediately.

Is there any harm in taking part in the study?

There is a small possibility that my presence may cause uneasiness to residents and/or staff, however I will make every effort not to interfere with the daily running of the home and observations will be discontinued immediately if people show signs of distress that may be thought to have been caused by my presence, e.g. perceived change in routine

What is the purpose of the observations?

The purpose of the observations is to understand the contexts in which challenging behaviours may occur, if there are any factors in the person's care environment that may prevent or cause challenging behaviour. Observations provide an objective perspective not filtered by the lived experiences of those observed and they can help us gain a better understanding of challenging behaviour and the circumstances in which it occurs.

What do I need to do?

If you agree for observations to take place in the home you manage, it would be helpful if prior to my visit you could inform staff and residents that the study will take place. Nothing is expected from you during the observations.

What will happen to the information gathered?

All data will be collected and stored in accordance with the Data Protection Act 1998. The information that we collect from you is confidential and anonymous. Only the research team (myself and my supervisors) will be able to access this information.

We will produce a report of the findings and will send you a summary. Also, we will publish scientific papers based on this work. All personal information will be anonymised at all times.

If we observe someone being harmed or we are told about someone being harmed we have a duty to disclose this to the care home manager. We respect confidentiality but must make sure that everyone is safe and looked after well in their home.

Reporting of findings from the larger PBS study will begin from summer 2016 and I hope to be discussing my findings early next year.

Contact details

Please feel free to contact me if you have any questions about the study.

Victoria Ratti

Telephone: 020 7679 9319

Email: v.ratti.11@ucl.ac.uk

Thank you for taking the time to read this information sheet.

Home Manager Consent Form

Participant Identification Number:

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study)

Please initial box

I have read the information sheet about this study and/or the project has been explained to me

I have had chance to ask questions and talk about this study

I am happy with the answers to all my questions

I have got enough information about this study

I understand that I can ask the researcher to stop the study whenever I want I do not have to give a reason. It will not change the health and social care service user receives

I agree for the researcher to conduct observations in this facility

I understand that I am free to withdraw from the study without penalty if I so wish and I consent to the processing of my personal information for the purposes of this study only and that it will not be used for any other purpose. I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998

Signed _____ Date: _____

Name in Block Letters: _____

Researcher's Name: _____

Researcher's signature: _____ Date _____

Paid carer information sheet

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study).

I am a research assistant from the Positive Behaviour Support (PBS) study which has involved one or more carers and service users from the facility you work in. As part of my PhD project, I am exploring challenging behaviour in people with learning disabilities in relation to the care environment; some carers who helped with the PBS study have also completed some questionnaires on person-centred support. I now need to carry out additional work such as observations in order to supplement the findings from the carers' responses.

I 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. Talk to others about the study if you wish.

Ask me if there is anything that is not clear or if you would like more information. Take time to decide whether or not you wish to take part.

About the study?

We aim to improve our understanding of challenging behaviour in people with intellectual disabilities and to explore the circumstances in which challenging behaviour is likely to occur, the characteristics of the living and care environment in which people with intellectual disabilities and challenging behaviour are currently living in and how challenging behaviour is responded to by staff.

It is important to investigate whether there are certain circumstances or certain characteristics of the living environment and the care provided by staff that may act as protective factors against the occurrence of challenging behaviour.

Who can take part in this research?

I would like to observe adults with intellectual disabilities and challenging behaviour who have already taken part in the PBS study.

Why have I been asked?

I have approached you to take part in this study because your work involves caring for people with learning disabilities. You may have also completed previous questionnaires on person centred support and choice.

Do I have to help?

No. It is up to you to decide to help us with the study.

What will happen to me / what will I have to do if I take part?

I will carry out observations in the participants' home, I will arrange a time to visit; this will usually be in the early evening before dinner time as previous research has found that this time of the day offers a good representation of the typical day of people with learning disabilities. However, I will be happy to negotiate another time, if there are reasons why this may be more appropriate and to avoid any possible disruption.

I will be at the participants' home for a period of approximately one hour and observe the typical environment, taking notes of the participant's behaviour, activities, interactions with other residents or staff and of the care provided by staff.

To minimise the impact of my presence there will be some time (10-15 minutes) before I start the observations to allow residents and staff to familiarise themselves with me and to get comfortable with me being around. When the observations begin, I will be as unobtrusive as possible, so that residents and staff will not feel influenced by my presence as the aim of the research is to observe the typical environment of the participant.

Observations will only be conducted in communal areas and if at any time residents or staff show any signs of distress due to my presence, I will stop the observations immediately.

If you agree to participate, I may include notes about any part of your interactions with the participant. If you agree to be part of this observational study you will also be agreeing to the use of any previous information obtained from questionnaires you may have completed previously, inasmuch as the present study is linked to the previous project you may have taken part in.

Is there any harm in taking part in the study?

There is a small possibility that my presence may cause uneasiness to residents and/or staff, however I will make every effort **not to** interfere with the daily running of the home and observations will be discontinued immediately if people show signs of distress that may be thought to have been caused by my presence, e.g. perceived change in routine

What are the possible benefits of taking part?

We cannot promise the study will help but the information we get might help improve things for people with challenging behaviour and those who provide support for them in the future.

What is the purpose of the observations?

The purpose of the observations is to understand the contexts in which challenging behaviours may occur, if there are any factors in the person's care environment that may prevent or cause challenging behaviour. Observations provide an objective perspective not filtered by the lived experiences of those observed and they can help us gain a better understanding of challenging behaviour and the circumstances in which it occurs.

Will information be kept confidential?

Yes. All information and observations will be kept confidential and anonymised so the names of you and the person who you are caring for will not be disclosed to anyone else and neither will either of you be identified in any report/publication. Professional standards of confidentiality will be adhered to and the handling, processing, storage and destruction of data will be conducted in accordance with the Data Protection Act (1998). Some study documents may also be looked at by authorised representatives from University College London (UCL) Research & Development Unit to check that the study is being carried out correctly. Professional standards of confidentiality will be followed by the authorised representatives. The information you provide will only be used for the purposes for this research study and not for any other purpose.

If we observe someone being harmed or we are told about someone being harmed we have a duty to disclose this to the care home manager. We respect confidentiality but must make sure that everyone is safe and looked after well in their home.

What will happen to the results of the research study?

I intend to publish results in relevant conference proceedings and publications. Please tell me if you would like a copy of any publications and I would be happy to send this to you when it is published. You will not be identified in any report/publication.

Contact details

Please feel free to contact me if you have any questions about the study.

Victoria Ratti

Telephone: 020 7679 9319

Email: v.ratti.11@ucl.ac.uk

Thank you for considering taking part and taking the time to read this sheet.

Paid carers opt-out form

<p>Person-centred support and challenging behaviour in adults with learning disabilities: an observational</p>

As explained in the Paid Carer Information Sheet which you have been provided with I will be conducting observations of one or more residents in the home you work in. I will be collecting information of the participant's behaviour, activities, interactions with other residents or staff and of the care received.

If you do not return this form any interaction that you may have with the observed participant may be observed by the researcher who may collect information on the quality on the nature and content of the interaction and care delivered.

No personal or identifiable information will be collected about you.

Please return this form to Victoria Ratti as soon as possible if you do not wish to be observed.

I understand that Victoria Ratti will be conducting the above study in the facility I work in.

I **do not wish** to be included in the study.

Name in block letters: _____ Date: _____

Signature: _____

Personal Consultee Information Sheet

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study)

Introduction

We feel your relative/friend/person you care for is unable to decide for himself/herself whether to participate in this research.

To help decide if he/she should join the study, we'd like to ask your opinion whether or not they would want to be involved. We'd ask you to consider what you know of their wishes and feelings, and to consider their interests. Please let us know of any advance decisions they may have made about participating in research. These should take precedence.

If you decide your relative/friend/person you care for would have no objection to taking part we will ask you to read and sign the consultee declaration which you have been sent with this information. We'll then give you a copy to keep. We will keep you fully informed during the study so you can let us know if you have any concerns or you think your relative/friend should be withdrawn.

If you decide that your friend/relative/person you care for would not wish to take part it will not affect the standard of care they receive in any way.

If you are unsure about taking the role of consultee you may seek independent advice.

The role of the consultee is to advise the research team as to the individual's likely wishes/ feeling with regard to taking part in the study. The consultee is not being asked to consent on the individual's behalf but give advice about their wishes. However the consultee's opinion will be respected in making a decision as to whether the individual should enter the study.

The following information is the same as would have been provided to the home manager of the facility where your relative/friend/person you care for lives.

Please also see the easy-read information we have provided to the relative/friend/person you care for.

Study information:

I am a research assistant from the Positive Behaviour Support (PBS) study which your relative/friend/person you care for took part in recently. As part of my PhD project, I am exploring challenging behaviour in people with learning disabilities in relation to the care environment; some carers who helped with the PBS study have also completed some questionnaires on person-centred support. I now need to carry out additional work such as observations in order to supplement the findings from the carers' responses. I would like to invite you to consider the possibility of me carrying out observations in the home where the participant lives.

Before you decide whether you think your relative/friend/person you care for would like to be involved we would like you to understand why we are doing the research and what it would involve for the participant. Please contact me if there is anything that is not clear – contact details at the end.

What is the study about?

The study is part of my PhD project which adds to the larger PBS study which your relative/friend/person you care for has already taken part in.

The aim of the observations is to explore the circumstances in which challenging behaviour is likely to occur and the characteristics of the living and care environment in which people with intellectual disabilities and challenging behaviour are currently living in.

It is important to investigate whether there are certain circumstances or certain characteristics of the living environment and the care received that may act as protective factors against the occurrence of challenging behaviour

Who can take part in this research?

I would like to observe adults with intellectual disabilities and challenging behaviour who have already taken part in the PBS study.

Do I have to help?

No. We are only asking you for your opinion as to whether you think your relative/friend/person you care would object to being involved in the research, if you think they would have no objection we would only ask you to sign a consultee declaration form and we will consider your advice. It is up to you to decide whether or not you would like to advise the research team.

What will happen if my friend/relative takes part in the study?

If you agree for me to carry out the observations in the participants' home, I will arrange a time to visit; this will usually be in the early evening before dinner time as previous research has found that this time of the day offers a good representation of the typical day of people with learning disabilities. However, I will be happy to negotiate another time with the home manager, if there are reasons why this may be more appropriate and to avoid any possible disruption.

I will be at the participants' home for a period of approximately one hour and observe the typical environment, taking notes of the participant's behaviour, activities, interactions with other residents or staff and of the care received.

To minimise the impact of my presence there will be some time (10-15 minutes) prior to the start of the data collection to allow residents and staff to familiarise themselves with me and to get comfortable with me being around. When the observations begin, I will be as unobtrusive as possible, so that residents and staff will not feel influenced by my presence as the aim of the research is to observe the typical environment of the participant.

Observations will only be conducted in communal areas and if at any time residents or staff show any signs of distress due to my presence, I will stop the observations immediately.

Is there any harm in taking part in the study?

There is a small possibility that my presence may cause uneasiness to residents and/or staff, however I will make every effort **not to** interfere with the daily running of the home and observations will be discontinued immediately if people show signs of distress that may be thought to have been caused by my presence, e.g. perceived change in routine

What is the purpose of the observations?

The purpose of the observations is to understand the contexts in which challenging behaviours may occur, if there are any factors in the person's care environment that may prevent or cause challenging behaviour. Observations provide an objective perspective not filtered by the lived experiences of those observed and they can help us gain a better understanding of challenging behaviour and the circumstances in which it occurs.

What will happen to the information gathered?

All data will be collected and stored in accordance with the Data Protection Act 1998. The information that we collect from your friend/relative will be confidential. Only the research team (myself and my supervisors) will be able to access this information.

If we observe someone being harmed or we are told about someone being harmed we have a duty to disclose this to the care home manager. We respect confidentiality but must make sure that everyone is safe and looked after well in their home.

We will produce a report of the findings and will send you a summary. Also, we will publish scientific papers based on this work. All personal information will be anonymised at all times. Reporting of findings from the larger PBS study will begin from summer 2016 and I hope to be discussing my findings early next year.

Contact details

Please feel free to contact me if you have any questions about the study.

Victoria Ratti

Telephone: 020 7679 9319

Email: v.ratti.11@ucl.ac.uk

Thank you for taking the time to read this information sheet.

Capacity to give consent to participate in research and the role of the consultee.

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study

We would be very grateful if you would act as a nominated consultee. Please could you read this information sheet which outlines the provisions for people who lack capacity to consent to participate in a research project and the role of the consultee.

Capacity to give consent

Usually an adult must give their informed consent before they can be entered into a research study. However many adults with learning disability lack the mental capacity to make such a decision. This does not mean that adults who lack capacity must be excluded from taking part in research but it does mean that certain processes - designed to safeguard both the person lacking capacity and the person making the decision for them - must be followed.

Firstly we cannot assume that an adult with learning disability lacks capacity to make such a decision. If there is a suspicion that the individual lacks capacity the two stage test of capacity must be applied as set out in the Mental Capacity Act. If, after assessment, the individual is deemed not to have the capacity to consent to taking part into the study then the researcher must appoint a consultee.

Consultees: definition and role

A consultee can either be 'personal' or 'nominated'. A *personal consultee* is someone unconnected with the research who knows the potential research subject in personal capacity and is able to advise on the person's wishes or feelings. This could be friend, family member or court appointee.

A '*nominated consultee*' is someone unconnected with the research appointed by the research team to advise the researcher about the persons wishes and feeling in relation to the project. This could be another professional but they must not have any connection with the study.

The research team has taken reasonable steps to identify a personal consultee in the first instance. However since we have not been able to identify a personal consultee we would like to invite you to act as a nominated consultee

The role of the consultee is to advise the research team as to the individual's likely wishes/ feeling with regard to taking part in the study. The consultee is not being asked to consent on the individual's behalf but give advice about their wishes. However the consultee's opinion will be respected in making a decision as to whether the individual should enter the study.

Please review the information sheets given to the participant and the manager of the home where the participant currently lives which describe in detail the purpose of the study and what it involves.

You will be given the opportunity to discuss the project with the researcher so that you can form an opinion as to the individual's likely wishes/feelings in respect to the project. If, at the end of this process, you feel that the individual would like to take part in the project you will be asked to sign a form to that effect.

Contact details

If you would like further information or want to discuss this please feel free to contact:

Victoria Ratti
Research Assistant PBS Study and PhD Candidate

UCL Division of Psychiatry
6th Floor Maple House
149 Tottenham Court Road
W1T 7NF

Email: v.ratti.11@ucl.ac.uk
Tel: +44 (0)20 7679 9319

Consultee declaration form

Name of participant:

Please initial the box to indicate that you agree to each statement:

I confirm that I have agreed to act as a consultee for the above named person. I understand that my role as consultee is to advise the research team as to the above named persons' likely wishes and feelings in relation to taking part in the study.

I confirm that I have had the opportunity to read the study information sheet and discuss the study with one of the investigators. I confirm that I am aware of the individual to contact should I have further questions about the study or in the event of a research related injury to the participant.

I understand that participant's personal information will be held securely for the purposes of conducting this study and to enable the research team to contact participants about related future studies.

I understand that data gathered or generated about the participant will be stored on a secure database.

I understand that the participant is free to withdraw from the study at any point without compromising his/her care and that I should contact the research team should I believe that the participant does not want to continue in the study.

I confirm that I have had sufficient time for considering my advice to the research team.

I understand that relevant sections of the participant's medical notes and data collected during the study, may be looked at by individuals from University College London, from regulatory authorities or from the NHS Trust, where it is relevant to the participant taking part in this research

I confirm that I have explained the purpose of the study and provided and outlined the potential risks and benefits (where applicable).

Name _____

Signature: _____

Date: _____

Name of investigator: _____

Signature: _____

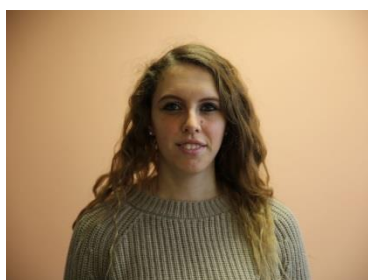
Date: _____

Service User Information Sheet

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study).



Observations



My name is Victoria and I work on the Positive Behaviour Support (PBS) study which you took part in



I am now doing another study for my doctorate degree



This study uses observations of what people with learning disabilities and their carers do together at home



I will look at the choices you make and how you get help to help to decide what you want to do



I will take some notes on what you do



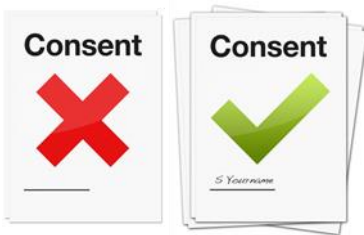
The study will help us understand how people manage their lives at home and the help they receive



If you agree I will come to see you at home 1 time



This will take about 1 hour



You do not have to take part if you do not want to, you do not have to give a reason and this will not change the care you receive



I will write about what I looked at but I will not use your name



If I see, or you tell me about anyone harming you I cannot keep a secret. I will have to tell the home manager



I will only visit your home one time for 1 hour












I will follow rules when I do the research – this is to make sure I do things properly.

Service user consent form

Participant Identification Number:

Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study).

		No	Yes
Please answer all the questions			
	I have read the information sheet about the research		
	I had the information sheet about the research explained to me		
	I can understand the things the information sheet told me		

		✗	✓
	<p>I was able to ask questions about the research</p>		
	<p>I understand that it is my choice to take part in this research</p>		
	<p>I understand that I can say No at any time if I want to stop</p>		
	<p>I understand that it will not change the care I get</p>		



date



my name
my signature



researcher's name
researcher's signature

D5. Letter of approval from NRES London-Harrow Ethics Committee



Health Research Authority

London - Harrow Research Ethics Committee

Level 3, Block B
Whitefriars
Lewins Mead
Bristol
BS1 2NT

Telephone: 0207 104 8049

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

24 November 2016

Prof Angela Hassiotis

UCL
Division of
Psychiatry
149
Tottenham
Court Road
London
W1T 7NF

Dear Prof Hassiotis

Study title: **Person-centred support and challenging behaviour in adults with learning disabilities: an observational study (student study).**

REC reference: **16/LO/1488**

IRAS project ID: **206971**

Thank you for responding to the Committee's request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this opinion letter. Should you wish to provide a substitute contact point, require further information, or wish to make a request to postpone publication, please contact the REC Manager, Sadie McKeown-Keegan, nrescommittee.london-harrow@nhs.net

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Mental Capacity Act 2005

I confirm that the committee has approved this research project for the purposes of the Mental Capacity Act 2005. The committee is satisfied that the requirements of section 31 of the Act will be met in relation to research carried out as part of this project on, or in relation to, a person who lacks capacity to consent to taking part in the project.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

- Please remove the typographical error in the following heading in the personal consultee's Participant Information Sheet "What will happen if I my friend/relative takes part in the study?".

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database within 6 weeks of recruitment of the first participant (for medical device studies, within the timeline determined by the current registration and publication trees).

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to contest the need for registration they should contact Catherine Blewett (catherineblewett@nhs.net), the HRA does not, however, expect exceptions to be made. Guidance on where to register is provided within IRAS.

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

Ethical review of research sites

[Omit this sub-section if no NHS sites will be taking part in the study, e.g. Phase 1 trials in healthy volunteers]

NHS sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS sites

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Covering letter on headed paper [Cover Letter]	1	25 July 2016

Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance]	1	16 June 2016
IRAS Application Form [IRAS_Form_27072016]		27 July 2016
IRAS Checklist XML [Checklist_04112016]		04 November
Non-validated questionnaire [Coding system for observations]	1	25 July 2016
Other [Home manager consent form]	1	06 July 2016
Other [Consultee declaration form]	1	25 July 2016
Other [Home manager info sheet]	2	10 October 2016
Other [Nominated consultee information form]	1	10 October 2016
Other [Paid carer opt out form]	1	10 October 2016
Other [Response to points made by Ethics Committee]	1	14 October 2016
Other [Personal consultee information sheet]	3	04 November
Other [Paid carer information sheet]	2	04 November
Other [Response to request for further clarification]	1	04 November
Participant consent form [Service-user Consent Form]	1	25 July 2016
Participant information sheet (PIS) [Service-user Info sheet]	2	10 October 2016
Referee's report or other scientific critique report [PhD upgrade panel report]	1	24 February 2016
Research protocol or project proposal [JRO approved]	3	04 November
Summary CV for Chief Investigator (CI) [Chief Investigator]	1	23 May 2016
Summary CV for student [CV Victoria Ratti]	1	27 July 2016
Summary CV for supervisor (student research) [CV Jason]	1	27 July 2016
Summary, synopsis or diagram (flowchart) of protocol in non-technical language [Study flowchart]	1	28 July 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical

review

Reporting

requirements

The attached document "*After ethical review – guidance for researchers*" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

16/LO/1488	Please quote this number on all correspondence
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With the Committee's best wishes for the success of
this project. Yours sincerely

**Pp Dr
Jan
Downer
Chair**

[Email:nrescommittee.london-harrow@nhs.net](mailto:nrescommittee.london-harrow@nhs.net)

Enclosures: "After ethical review – guidance for
researchers"

Copy to: Miss Jenise Davidson, Portfolio coordinator/ Joint Research Office