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

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.

Highlights

- There were 7 quantitative, 5 qualitative and 4 mixed methods studies.
- PCP was most effective for community participation.
- The methodological quality of the included studies was moderate to weak.
- The evidence for wide implementation of PCP remains inconclusive.

Keywords

systematic-review, person-centred planning, intellectual disability, learning disability, care, outcomes.

1. Introduction

In the last few decades there has been an ongoing transformation of services for people with intellectual disabilities (ID), with service delivery progressively shifting from a system-centred approach to a person-centred approach tailoring services around the individual, rather than enforcing *one size fits all* structures (Kaehne & Beyer, 2014) . Individualised support has been widely acclaimed and has become common parlance in services for people with ID. Person-Centred Planning (PCP) is the latest approach aimed at achieving 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 (DOH, 2009), US and Australia (Holburn, Jacobson, Schwartz, Flory, & Vietze, 2004).

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. 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). 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); see Sanderson (2000) for a summary of 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 on 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) only 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, Van Hove, Vandevelde, van Loon and Schalock (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 & Fox, 2003; Buschbacher, 2004; 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 (DOH, 2009, 2012; 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 such publications.

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. The aim of the present paper is to conduct a systematic review of all studies which investigated the impact of PCP on people with ID.

The objectives are as follows: (a) to provide an updated review of status of research concerning the effectiveness of PCP on outcomes for people with ID, (b) to determine whether PCP and its components are effective on improving outcomes for people with ID, (c) to determine what outcomes are most likely to be affected by PCP, (d) to identify directions for future research.

2. Method

2.1. *Search strategy*

The electronic databases PsycInfo, Embase, CINHAL, 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. 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 A 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).

2.2. *Inclusion and Exclusion Criteria*

- Population: studies were included if all 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). We excluded studies which were purely descriptive and those which reported outcomes of author defined traditional planning approaches such as Individual Personal Planning and Individual Habilitation. 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.

2.3. *Outcomes*

Primary outcomes which were expected to be influenced by PCP, based on the teams' 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.

2.4. Review Process

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 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.

Figure 1. Study selection (PRISMA flow chart)

2.5. Analysis and quality assessment.

We developed a structured data extraction form 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. One reviewer completed the process (VR) and accuracy of the data extraction was assessed by a second reviewer (PG).

Criteria developed by Downs and Black (1998) were adopted to evaluate the methodological quality of quantitative non-randomised studies listed in Appendix B1; they cover reporting, external validity and internal validity. 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 B2.

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 two authors (VR, PG). 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 between raters was achieved.

2.6. Ratings of the impact of PCP on outcomes

We adopted a rating scale developed by Prout and Nowak-Drabik (2003) 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 two researchers (VR, PG) and where discrepancies occurred these were discussed until consensus was reached.

3. Results

3.1. Overview of studies

The current review identified sixteen studies which met the inclusion criteria, seven of which were quantitative in nature, five qualitative and four mixed methods studies. Additionally four case studies 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 2014, in the UK, US, New Zealand and Canada and included a total of 598 participants, across the age range (8-84 years old), with various levels of

ID (mild to severe). Table 1 provides an overview of the included studies grouped by methodology. A more detailed description of the interventions used in each study is available from the authors.

Table 1. Summary of study characteristics grouped by methodology

Quantitative

Reference and Country	**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 catergorise 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 (*Personal Futures Planning;* N=20*)* and matched comparison group (traditional *Individual Service Planning*; 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 accomodation 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). -Variery 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% inlcusive, 14% segregated) compared to TM participants (32% inclusive, 68% segregated). -Choice: In the AM 67% of activities participants were enagaged 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 *Person-centred Career Plans* 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 *Person-centred Planning* (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 childeren’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. *Every 3 months:*Health Survey for England (scheduled day activities, physical activity); Index of Community Involvement (ICI), Social Network Map, Client Receipt Inventory. *Every 6 months:*all of the above plus Strenghts 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 (flatting/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.	*Microboards person-centred approach in* Homes and community settings	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 view 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 stakeholder s’ 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, McCone, Ferguson 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**
Heller, Miller, Hsieh and Sterns (2000). USA.	PCP training for individuals with ID, fstaff and family memebers.. 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.

3.2. Variations in PCP evaluation

Eleven studies prospectively evaluated the effectiveness of PCP, two studies evaluated the effect of training individuals with ID, staff and family members in delivering PCP (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).

3.3. Quality of studies

Table 2 and 3 show the scores for the quality appraisal for quantitative and qualitative studies respectively. Higher scores indicate higher study quality.

3.3.1. Quantitative studies

Table 2. Quality assessment of quantitative studies

Reference	Reporting/10	External Validity/3	Internal Validity/14	Total/25
Adams et al. (2006)	8	0	6	14
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 study was presented as a mixed methods study the qualitative aspect of the study was minor and not related to outcomes for people with ID, therefore it was evaluated as a quantitative study.

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, Spinosa, & 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)).
- Limited or non-reporting of findings (all except Adams et al. (2006) and Heller et al. (2000)).

3.3.2. Qualitative studies

Table 3. Quality assessment of qualitative studies

Reference	Total Yes	Total No	Overall quality assessment
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 and 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)).

3.4. Outcomes

3.4.1. Outcome ratings

The most commonly investigated outcomes were daily choice-making, participation in activities and social networks/relationships. The former two outcomes were among those which appear 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. Details of the outcomes, measures and ratings of impact of PCP on outcomes are presented in table 4.

Table 4. Outcome ratings

Outcome variable/reference	**Measure**	**Score (1-5)**	**Mean score**
Quality of life			**3.6**
Parley (2001)	PCSR/NGT	3	
Malette (2002)	Participant Observation/Interviews	3	
Holburn et al. (2004)	Quality of Life Outcome Index	5	
Life satisfaction			**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	
Choice Making			**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	
Self-determination			**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	
Participation in Activities			**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	
Community Participation			**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	
Social Networks/Relationships			**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	
Behaviour			**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	
Adaptive Functioning			**1**
Adams et al. (2006)	Adaptive Behaviour Scale	1	

Employment			**2**
Robertson et al. (2006)	Demographics	1	
Menchetti and Garcia (2003)	Document Analysis of expressed job preference and obtained employment match	4	
Magito-McLaughlinget al. (2002)	Direct Observation	3	
Kaehne and Beyer (2014)	Content Analysis	1	
Heller et al. (2000)	Expressed Goals	2	
Malette (2002)	Participant observation/ interviews	1	
Health			**-1.5**
Robertson et al. (2006)	Health Survey for England	-4	
Truesdale-Kennedy et al. (2006)	Thematic Content Analysis	1	

PCSR= Person-Centred Service Review
NGT = Nominal Group Technique
*Adapted from the Life Satisfaction Scale for Aging Adults with Mental retardation

3.4.2. 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 training (n=42). In a subsequent study with a similar methodology no significant difference was found between life satisfaction scores for participants in PCP training (n=38) and a comparison group (n=22); there was also no significant main effect for time (Heller et al., 2000). Table 5 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 5. Life Satisfaction Intervention vs. Comparison group

	Control			**Intervention**		
Study	**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 of 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 experienced 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 delivered to 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.

3.4.2. 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) 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 by Menchetti and Garcia (2003). They 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 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 that there were significant barriers to implementing employment related goals such as changing jobs or workplace as there was a 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.

4. Discussion

4.1. Summary of findings

In this review we have endeavoured to provide a broad overview of the status of research on PCP for people with ID, to identify outcomes most likely to be influenced by PCP and to evaluate its effectiveness. Sixteen studies were included in this review which suggests 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 every-day 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.

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 .

We are unable to show any associations between PCP effectiveness and age, level of ID or PCP approach used. The review includes research that explored the effectiveness of PCP in a variety of settings, however due to the small number of studies it is 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.

4.2. 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 of transition (e.g. leaving school, moving to employment, adjusting to later-life) and this may have differential effects from PCP applied in an established setting where a pre-existing system is already in place. Outcomes measures differed across studies, thus it has not been possible to combine findings. The ratings in table 4 constituted an attempt to summarise the impact of PCP for each outcome; the reviewers however did not assign weights 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. Onlly 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 included studies 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. Studies also presented a risk for response bias as only three studies gathered responses directly from the 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 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 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 also poses a challenge to future replications and confirmation of findings.

4.3. 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 and only 5% received two annual updates suggesting that there might be over-emphasis on the first 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. Moreover, 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-years follow-up there were still a high proportion of goals that had not been met. The failure to carry plans through into practice (implementation gap) has been the cause for strong criticism of PCP as a mere paper exercise (Mansell & Beadle-Brown, 2004b). Authors have argued that successful outcomes can be achieved even in the absence of formalised planning systems and have instead placed greater emphasis on person-centred action interventions such as Active Support (Mansell & Beadle-Brown, 2004a).

4.4. The role of care-givers

Care-givers constitute a major influencing factor on the success of PCP and they play a vital role in shaping the lives of people with ID through the quality of support that they provide. Heller et al. (2000) found that individuals with ID regarded staff's instrumental and emotional support as the single most important facilitator of goal attainment. Dumas, De La Garza, Seay, and Becker (2002) argued that individuals with ID do not perceive having a plan as the main cause of change, but in fact responsibility for change, achievements and failure to achieve is attributed to the PCP facilitators whose commitment to PCP has been considered the most powerful predictor of successful outcomes for people (Sanderson, Thompson, & Kilbane, 2006).

4.5. PCP within organisational structures

According to Parley (2001) in order for PCP to be successful, it should not be only frontline staff who adopt it, but the approach should be embraced at all levels of the organisations providing care, from direct-carers to service planners. In agreement with this notion, Kaehne and Beyer (2014) argued that PCP can only truly influence outcomes for people with ID if all stakeholders fully embrace it as an integral part of service delivery and fully commit to its implementation; PCP is an evolving and on-going process which has to be sustained overtime so if it is not supported and adopted as part of the services' culture it will most likely incur the risk of losing effectiveness and eventually fail to have any meaningful impact (Rea et al., 2002; Sanderson et al., 2006).

It is a significant challenge for services to find appropriate ways to maintain the person-centred culture and commitment by all members of staff especially in working environments where staff turnover is high (Sanderson, 2000). Furthermore care for the same individual is often provided in different environments and by different teams who may espouse different philosophies. PCP may actually highlight limitations and gaps between services. Kaehne and Beyer (2014) called attention to the fact that there was a lack of adult social services and employment agencies at post-school transition meetings for young people with ID. They argued that this was likely to constitute a significant barrier to the implementation of goals articulated at meetings due to the poor connection between services. Moreover their lack of involvement was regarded as likely to limit the options available to young people leaving school, narrowing their choices and reflecting a system based on the availability of services rather than on the choices and preferences of individuals.

Parley (2001) argued that a successful implementation of PCP requires more than just a change in procedures; it also requires a change in attitudes, values, knowledge and competence. This nonetheless may be more difficult to achieve where services already have established practices in place and may be more resistant to change. For such reasons Black et al. (2010) suggested that in order to successfully implement PCP it may be easier, where possible, to develop new services rather than transforming existing ones where practices and roles are already established.

4.6. Recommendations for future research

Policy initiatives require robust underpinning by research evidence and therefore, given the promotion of rolling out PCP, it is important to support this with more information on its delivery and implementation. In light of the paucity of experimental evidence of PCP the most obvious recommendation for future research is to utilise larger and randomly controlled samples in order to demonstrate the effectiveness of PCP as an evidence-based complex intervention. Randomisation inevitably poses ethical and practical issues, nevertheless where the evidence for the effectiveness of PCP is so limited, it is ethically justifiable where comparison groups continue to receive standard care; participants' preferences however may render it infeasible (Sibbald & Roland, 1998). Careful consideration should therefore be given to the selection of adequate control conditions and the design of future studies. Some have argued that regardless of study design, future PCP research should prioritise longitudinal evaluations (Taylor & Taylor, 2013).

Other issues related to the delivery of PCP are sufficient availability of staffing and resources. In the present review only one study was found which assessed implementation costs of PCP (Robertson et al., 2006). Alhtough the study found no significant difference between the average service package cost per participant before and after PCP implementation, it is impossible to draw solid conclusions regarding cost and cost-effectiveness. Further research should strive to evaluate and optimise service delivery costs, particularly as PCP is neither easy nor brief and arguably affected by resource availability (Holburn & Cea, 2007).

Finally, manualised versions of PCP may help to define and standardise its content and delivery. A potential framework to systematically develop a structured PCP intervention could be found in 'Intervention Mapping' (Bartholomew, Parcel, & Kok, 1998).

Medical Research Council (MRC) guidelines for complex interventions recommend that interventions should strive to be replicable; future studies should therefore aim to provide accurate descriptions that will allow the readers to gain an understanding of their components (Craig et al., 2008). It is necessary to distinguish which 'active ingredients' of PCP determine outcomes (Holburn, 2002). Process evaluation may be a useful way to clarify what renders the intervention successful and identify ways it can be optimised (Moore et al., 2015). The implementation of PCP must take into consideration the broader context in which the individual receives care, e.g. the healthcare system and the community where the individual lives. Understanding these contexts could prevent interventions from failing to achieve their full potential(Gask & Coventry, 2012; Li & Porock, 2014, 2014).

4.7. Conclusion

Empirical support for the effectiveness of PCP is still fragmented even though attempts have been made to quantitatively measure its impact. However despite the policy argument for the wide adoption of PCP, there is uncertainty of the long-term outcomes and the ways in which challenges in implementation 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 et al., 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 two new studies have been conducted in the UK (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 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 (DOH, 2001).

More rigorous large scale evaluation is needed in order to truly establish its clinical and cost effectiveness and elucidate how it can be rolled out within a variety of health and social care systems.

Conflict of interest

The authors declare that there are no conflicts of interest.

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