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ARTICLE

Reported goal setting and benefits of person centred planning for people with intellectual disabilities

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Abstract Recent research suggests that person centred planning (PCP) can have a positive impact on the lives of people with intellectual disabilities. This article presents data from open-ended comments collected during research on the impact of PCP on the life experiences of 65 people with intellectual disabilities living in

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England. These comments addressed the goals set prior to and during PCP, and the main benefits of PCP for participants. The results suggest that PCP led to increased goal setting in a range of goal categories. This was reflected in the most common main benefit of PCP of 'increased activities and opportunities' reported for 57 percent of participants. For 48 percent of participants, a main benefit of PCP was that they felt better in themselves, in terms of happiness or self-esteem. This must surely be the ultimate aim of those seeking to improve the quality of life of people with intellectual disabilities.

Keywords intellectual disabilities; person centred planning

Introduction

The development of systems for personalizing services and supports to the needs and aspirations of service users has become fundamental to current health and social care policies in the UK, including policies specifically addressing the inequalities faced by people with intellectual disabilities (Cabinet Office, 2005; Department of Health, 2001; Scottish Executive, 2000). In England, person centred planning (PCP) is central to the 2001 White Paper that set out the government's strategy for the development and delivery of health and social care services for people with intellectual disabilities (*Valuing People*: Department of Health, 2001). A key component of this strategy was to require statutory services to introduce PCP across England as a means of increasing the extent to which supports were tailored to the needs and aspirations of people with intellectual disabilities. Many US states also mandate the use of person centred planning (Schwartz et al., 2000). Despite the importance afforded to PCP in policy and practice, there was until recently little or no robust evidence either of the impact of introducing PCP or of those factors which may either facilitate or impede the introduction and effectiveness of PCP (Robertson and Emerson, 2007; Robertson et al., 2006). The first systematic review of the evidence base for lifestyle planning approaches (including PCP) found only five studies with a total of 108 subjects which reported any outcome data for any form of lifestyle planning (Rudkin and Rowe, 1999). Rudkin and Rowe conclude that: 'There is no quantitative evidence to support the use of lifestyle planning in general or in any individual form' (1999, p. 366). In relation to PCP, as noted by Holburn et al. (2004), research evaluating quality of life outcomes as a result of PCP has been qualitative with the exception of a single case investigation (Holburn and Vietze, 2002).

Recent research from the US and UK has, however, now demonstrated the potential for PCP to improve the lifestyle related outcomes for people

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with intellectual disabilities. A study by Holburn et al. (2004) in the US was the first to examine the relationship between a comprehensive PCP intervention and a range of outcomes. They conducted a longitudinal study of the impact of PCP for a group of 19 individuals living in institutional settings in the US. The PCP group were compared with 18 matched peers who received conventional individual service planning (ISP). Results indicated that PCP hastened the move to community settings, with 18 of the PCP group moving to the community compared to only five in the contrast group. Outcome measures indicated that the quality of life indicators of autonomy, choice-making, daily activities, relationships and satisfaction improved more for the PCP group than for the contrast group.

More recently, in England a longitudinal study of the impact of PCP on the lifestyles of people with intellectual disabilities has been completed and the quantitative findings presented in a series of publications which have looked at the impact and cost of PCP (Robertson et al., 2005; 2006), factors associated with successful outcomes of PCP (Robertson et al., 2007a), and reported barriers to the implementation of PCP (Robertson et al., 2007b). From the measures employed in the study, it was evident that the introduction of PCP had a positive impact on the life experiences of people with intellectual disabilities. Positive changes were found in the areas of: social networks; contact with family; contact with friends; community-based activities; scheduled day activities; and choice. The benefits identified in the research importantly came without additional service costs once initial training costs were taken into account. However, the benefits associated with PCP did not extend into certain areas of people's lives, such as employment and more inclusive social networks (Robertson et al., 2005; 2006). Further, the results indicate a strong influence of factors relating to the characteristics of participants, contextual factors, and the process of PCP on both access to and the efficacy of PCP (Robertson et al., 2007a). The results also indicate that people involved in the PCP process face a wide range of pervasive barriers to the implementation of PCP and the attainment of goals set in plans (Robertson et al., 2007b).

The findings regarding the impact of PCP on the life experiences of participants have thus far been based on analyses of measured outcomes, such as changes in hours per week of scheduled activities. This article presents information from open-ended reports collected during the course of the project regarding the impact of PCP in two areas: (1) descriptions of the goals set and met during PCP; and (2) the reported main benefits of PCP for participants. As such, the objective of this article is to ascertain whether there is any impact of PCP beyond the changes in predetermined outcome measures already reported for this study.

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Method

Selected elements of the method relevant to this article are given here. Full details can be found in Robertson et al. (2005). The project was a longitudinal study of the impact and cost of the introduction of PCP for 93 people with intellectual disabilities living in four localities in England. PCP development work was undertaken with organizations in the four localities to provide additional support to help them develop robust policies, procedures and practices to implement PCP. Training and support took place over a period of 2 years from March 2001 to March 2003. Training was provided to both facilitators and managers.

The introduction of PCP was phased across the four localities over a 12 month period. Participants were the first 25 people with intellectual disabilities in each locality for whom an attempt was made to develop a plan. In total, 93 people took part in the project, of whom 65 (70%) had a plan developed within the timescale of the project. Information was collected at approximately 3 month intervals for each participant following their recruitment into the study regardless of whether or not they had had a plan developed. Full details of the instruments used to measure outcomes can be found in Robertson et al. (2005). This article only includes information collected regarding the 65 participants who did receive a person centred plan.

Goals set and met

At each data collection round, information was collected from a key informant who knew the participant well (e.g. the person's key worker). Informants were asked two open-ended questions: (1) 'What new goals were set at the person's last planning meeting?'; and (2) 'What progress has been made towards meeting the goals in the plan?' Information was also collected on goals set in pre-existing individual plans prior to the implementation of PCP. Content analysis was used to identify general categories of goals from the responses given. This led to the goals being sorted into 19 mutually exclusive categories (see Table 1). The occurrence of these goal categories was analysed for all data collection rounds to see if each type of goal was set *at all* for each of the 65 participants who received a plan during the project: (1) prior to the implementation of PCP; or (2) following the implementation of PCP. The proportion of those for whom these goals were met post-PCP was also analysed. The role of informants in the person's life was not routinely recorded and as such it is not possible to link responses to informant roles.

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Benefits of PCP

At each 3 monthly data collection round, informants were asked an open-ended question: 'What do you think the main benefits of PCP have been for this person so far?' Open-ended responses were summarized (e.g. participant taking part in more activities; participant more confident) and a numerical code was assigned to each summary statement. A total of 96 summary statements were then analysed to identify emerging themes and each summary statement was allocated to a theme. The following themes were identified:

1 Empowerment and control: e.g. participant in charge of services; participant gets a say in life; participant gets fully heard.
2 Improved choice: e.g. gets more choice; get to do more of what they want to do.
3 A fresh look at the person and their life: e.g. increased knowledge and understanding of the person; a creative approach; looking beyond what the person already has.
4 Improved social life/social contact: e.g. new friends; increased contact with friends.
5 Increased activities and opportunities: e.g. goals achieved; getting to do new activities; things more likely to happen; goes out, used to just stay in.
6 Focus person feels better: e.g. more confident; more assertive; improved self-esteem; happier.
7 Facilitates communication with participant: e.g. allows participant to communicate; communication system introduced, e.g. pictures.
8 Altered perception of participant: e.g. more positive about focus person.
9 More people involved in their life or planning: e.g. building a circle of friends; input from others into their life; increased involvement of professionals.
10 Improved quality of life (unspecific): e.g. quality of life better.
11 Improved skills: communication skills improved; mobility improved; improved ability.
12 Structured and consistent approach: improved routine; consistent approach used with participant; communication between services.
13 Independence: increased independence.
14 Increased or improved service receipt/support: more individualized support; receiving advocacy services; getting more staff time.
15 Community presence: increased participation in community.
16 Giving focus person direction: gives the person direction or motivation; focuses person on dreams and ambitions; person knows what they need to do to move.

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17 Changing staff attitudes/motivation/commitment: improved team commitment; staff motivated; whole day centre becoming more person centred.
18 Addressing health issues: has a health action plan; health has improved.
19 Helps family: parents have learnt about e.g. direct payments, ILF; family are more positive about situation.
20 Behaviour improved: improved behaviour.

The occurrence of these themes was analysed for all 3 monthly questionnaire rounds to see if the theme occurred *at all* for each of the 65 participants who received a person centred plan during the timescale of the project.

Results

Table 1 shows the percentage of participants who had goals set in each category both before and after the implementation of PCP, and the

Table 1 **Percentage of participants for whom goal categories set pre- and post-PCP and met post-PCP**

Goal category	*% for whom goal set pre-PCP*	*% for whom goal set post-PCP*	*% for whom goal met post-PCP*
Leisure***	19	75	80
Social networks***	9	59	66
Setting***	6	54	43
Independence and skills**	25	51	73
Events and one-off activities***	15	51	76
Health*	20	37	54
Education***	8	37	54
Material acquisitions*	12	29	53
Day services***	5	26	59
Vocational***	3	26	41
Staff and support**	6	25	56
Communication	11	17	36
Service receipt	8	15	60
Risk	3	11	57
Self-care*	0	9	67
Choice	3	6	50
Religious needs	2	5	100
Empowerment	2	5	33
Behaviour	0	3	50

McNemar test significance for proportion having goal category set pre- and post-PCP: * = $p < 0.05$; ** = $p < 0.01$; *** = $p < 0.001$.

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percentage of those who had a goal set during PCP who had also had the goal met. These are rank ordered from the highest percentage of participants who had a goal category set post-PCP. After the introduction of PCP, the most common category of goal set was 'leisure' (75%) and over half of participants had goals set in the areas of 'social networks', 'events and one-off activities', 'independence and skills', and 'setting'.

For the majority of categories, a significantly higher proportion of participants had goals set post-PCP than prior to the implementation of PCP. McNemar tests for two related samples showed a significant difference between the proportion for whom a goal was set pre-PCP compared to the proportion for whom a goal was set post-PCP for the following: leisure; social networks; events and one-off activities; independence and skills; setting; health; education; day services; material acquisitions; staff and support; vocational; and self-care. In all cases a significantly greater proportion of participants had the goal category set post-PCP than prior to the implementation of PCP.

With respect to the reported benefits of PCP, Table 2 shows the percentage of the 65 participants for whom each theme was reported as a main benefit of PCP. The most common reported benefit was 'increased activities and opportunities' (57%), followed by 'a fresh look at the person and their life' (51%), and 'participant feels better – confident, happy' (48%). Over a third of informants noted benefits in the areas of 'empowerment and control' (37%) and 'choice' (37%).

Discussion

The results presented lend further support to the overall findings of the project that suggest that PCP can have a positive impact on the life experiences of people with intellectual disabilities. At least in the short term, PCP appears to lead to a flurry of activity aimed at improving quality of life, as evidenced by the significantly heightened levels of goal setting post-PCP in numerous categories. This is further evidenced in the reported main benefits of PCP, with the most common benefit being 'increased activities and opportunities'.

A number of the main benefits reported mirror the findings of the quantitative measures previously reported (Robertson et al., 2006), with benefits reported in the areas of activities, social networks, and choice. However, several of the most frequently reported main benefits were in areas which were not addressed by quantitative measures. First, PCP was seen to allow a fresh look at the person and their life for over half of participants and in some cases this meant that old 'reputations' were laid aside. Second, PCP was reported to have led to nearly half of participants feeling

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Table 2 **Percentage of participants for whom theme reported as a main benefit of PCP**

Benefit theme	*% for whom reported as a main benefit of PCP*
Increased activities and opportunities	57
Fresh look at person and their life	51
Participant feels better – confident, happy	48
Empowerment/control	37
Improved choice	37
More people involved in life and planning	26
Improved social life/social contact	22
Increased independence	22
Structure and consistent approach	17
Health issues	15
Improved skills	14
Altered perception of participant	12
Increased or improved service receipt	12
Community presence	11
Changing staff attitudes/motivation	11
Improved quality of life (unspecific)	9
Facilitates communication	8
Giving participant direction	8
Behaviour improved	6
Helps family	5

better, for example in terms of improved confidence or self-esteem, or being happier. Third, PCP was seen to lead to 'empowerment and control' and 'choice' for over a third of participants.

The results do need to be considered within the context of a number of methodological limitations inherent in the study. First, while the 2 year time span of the study compares well with previous research, it was only sufficient to evaluate the short-term and (to an extent) medium-term impact of PCP. As such, it is not clear whether the heightened level of goal setting and the benefits reported to be associated with PCP will be maintained in the long term. These positive benefits may reduce once the initial enthusiasm for PCP dissipates. Second, the confidence with which the results can be generalized to other organizations in England (and elsewhere) who are attempting to implement PCP in the early 21st century is dependent on the representativeness of the participants and the organizations, and the broader policy context within which the organizations were operating. In this context, our failure to randomly select localities, organizations and participants raises the possibility of selection bias. Finally, the data from open-ended questions are dependent on the willingness of respondents to write in information, and there may have been bias in

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respect of which respondents did and did not choose to complete these sections. This may have led to the underreporting of goals set prior to their involvement in PCP.

Nonetheless, these results add further strength to the overall conclusion from the analysis of quality of life related outcomes measured during the project that PCP can indeed benefit the lives of people with intellectual disabilities. The process can, at least in the short term, lead to a fresh look at people's lives and greater consideration of the activities and opportunities that people wish to experience. Perhaps the most pertinent finding is that for nearly half of the participants, a main benefit of PCP was that they felt better in themselves, in terms of happiness or self-esteem. This must surely be the ultimate aim of those seeking to improve the quality of life of people with intellectual disabilities. As such, there is a need to develop policy and practice to ensure that as many people as possible gain access to the quality of life related benefits that appear to be associated with PCP.

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