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6

Participatory Peer Research in the Treatment of Young Adults With Mild Intellectual Disabilities and Severe Behavioral Problems

Louis Tavecchio , Peer Van der Helm, Xavier Moonen, Mark Assink, Geert Jan Stams, Inge Wissink, Jessica Asscher

Abstract

This study provides an illustration of a research design complementary to randomized controlled trial to evaluate program effects, namely, participatory peer research (PPR). The PPR described in current study was carried out in a small sample (N = 10) of young adults with mild intellectual disabilities (MID) and severe behavioral problems. During the PPR intervention, control and feedback to individuals is restored by training them to become participant-researchers, who collaborate in a small group of people with MID. Their research is aimed at the problems the young adults perceive and/or specific subjects of their interest. The study was designed as a multiple case study with an experimental and comparison group. Questionnaires and a semistructured interview were administered before and after the PPR project. Results of Reliable Change Index (RCI) analyses showed a decrease in self-serving cognitive distortions in the PPR group, but not in the comparison group. These results indicate that PPR helps to compensate for a lack of adequate feedback and control, and in turn may decrease distorted thinking and thereby possibly later challenging behavior. © 2019 The Authors. New Directions for Child and Adolescent Development published by Wiley Periodicals, Inc.

Over the last five decades, the use of the Randomized Controlled Trial (RCT) has been growing in research on the effectiveness of psychological child and youth care interventions (Weisz et al., 2017). RCT is the hallmark of evidence-based treatment because of its strong internal validity (Lilienfeld, McKay, & Hollon, 2018). However, due to practical, political, legal, or ethical considerations, random assignment to an experimental and control group is sometimes considered impossible or undesirable. Moreover, RCTs may not always be feasible for rapid and timely knowledge acquisition under clinically representative conditions, and subsequent successful implementation of research outcomes (Hekler et al., 2016). For the case described in the present study, an RCT was not possible due to the limited number of participants.

Other study designs could function as alternative or complementary designs to RCT. For example, Participatory Peer Research (PPR) is an approach in which clients conduct the research themselves in order to secure a fast translation of the study results into clinical practice. It is hypothesized that individuals experience control and agency as they have an active role in the research, whereas in RCTs, they are more passive participants. PPR has thus a different function than RCTs: RCTs aim to provide information on overall effectiveness, which may take quite some time before coming available. PPR aims to provide immediate information, which also may modify cognitions of the participant researchers. The aim of our study was to evaluate the effects of PPR as an intervention in young adults with Mild Intellectual Disabilities (MID) and severe behavioral problems living in a residential care facility.

Our study was guided by Martin's I-D compensation theory (Martin, 1999), which states that, in general, individuals perceive a sense of control over their environment and are considered to function optimally if they are able to satisfy their immediate-return needs (the I in I-D). If they fail in satisfying these needs, because rewards are delayed in time (the D in I-D), they will, in the absence of real feedback, increase their reliance on imaginary mental processes, such as the simulation of feedback and problem solving through dissonance reduction. This can create distorted cognitions, lack of internal locus of control, low self-esteem, and eventually aggressive behavior (Roese & Olson, 1995).

In residential care, individuals with MID often lack control over their immediate social environment and are deprived of adequate feedback (Wehmeyer & Bolding, 2001), which may result in an external locus of control and self-serving cognitive distortions according to Martin's I-D compensation theory. This may be resolved by involving them in decisions about their daily lives, for instance, by implementing opportunities for participation (Dedding, Jurrius, Moonen, & Rutjes, 2013; Lauwers & Vanderstede, 2009), as is the case when they have the opportunity to become participant researchers in PPR.

Participation can be established by training individuals with MID in PPR and, subsequently, give them the opportunity to execute PPR projects, which can be achieved in several weeks or may take a longer period of time, depending on the participants involved and the subject of the study (Dedding et al., 2013). In PPR intervention projects, clients function as participant-researchers of problems or developments that occur within their immediate social environment. Clients who function as participant researchers collaborate with professionals (not being group workers) who function as coaches. These coaches support the client researchers in conducting research and encouraged them to show respect to each other and to interact assertively but friendly. With guidance of the PPR coach(es), the participant-researchers start brainstorming about subjects they would like to change and choose a study design. The client researchers gather the data themselves, draw conclusions, and formulate follow-up actions. The final step the client researchers take is presenting, reporting, and implementing the results themselves. We hypothesized that PPR would be associated with (1) more participation, (2) improvement in self-esteem, (3) decrease in external locus of control, and (4) decrease in self-serving cognitive distortions.

The present study evaluates the effects of PPR on cognitive distortions, self-esteem, and external locus of control in young adults with MID and severe behavioral problems residing in a residential care facility. It is assumed that some feedback, and therewith control, is restored by training them to become researchers who collaborate in a small group of co-researchers with MID. The object of their research is constituted by the problems they perceive in living in an institution, and/or with other subjects of their interest. By using a research design which is an intervention in itself, we acquire knowledge on the effects while collecting data. Although we are well aware that our study does not provide strong empirical evidence for the validity of PPR as a research method, our study aims to illustrate how PPR can be applied under a clinically representative condition, allowing immediate implementation of the study results.

Individuals With MID, Instant Gratification, and Self-Serving Cognitive Distortions. Individuals with MID often show an inability to pursue long-term goals, and are generally more focused on immediate gratification instead of delayed rewards, which renders them more vulnerable to ego-defensive tendencies and distorted cognitions (Parry & Lindsay, 2003; Van Nieuwenhuijzen, Orobio de Castro, Wijnroks, & Vermeer, 2009). Ego defensive tendencies and distorted cognitions are inaccurate or biased causal inferences in response to social problem situations, and can be divided into primary and secondary self-serving cognitive distortions (Barriga, Gibbs, Potter, & Liau, 2001; Nas, Brugman, & Koops, 2008). Primary distortions are self-centered attitudes and beliefs, while secondary cognitive distortions are used to prevent damage to the self-image (Barriga et al., 2001): (1) blaming others (i.e., misattributing blame to outside sources),

(2) minimizing/mislabeling (i.e., considering antisocial behavior as acceptable), and (3) assuming the worst (i.e., attributing hostile intentions to others, seeing worst-case scenarios as inevitable, or assuming that improvement is impossible). These cognitive distortions can result from immediate gratification frustration (see Pratt & Cullen, 2000), and are often considered important precursors of challenging or aggressive behavior (Langdon, Murphy, Clare, Steverson, & Palmer, 2011).

Young Adults With MID in Residential Care Institutions. Individuals with MID living in residential care institutions often experience a lack of feedback and control, because staff responsiveness to the needs of these individuals is often insufficient, and group climate is often characterized by repressive control (Knotter, Wissink, Moonen, Stams, & Jansen, 2013). Besides, research shows that living in an impoverished environment, in which adequate feedback and opportunities for application of newly acquired competences are insufficient, fosters learned helplessness (Van der Helm & Stams, 2012). Learned helplessness is thought to be associated with an external locus of control in individuals living in residential facilities (Page & Scalora, 2002; Van der Helm, Matthys, Moonen, Giesen, Heijde, & Stams, 2013; Van der Helm, Beunk, Stams, & Van der Laan, 2014). Lack of adequate feedback and control may be resolved by involving individuals with MID in decisions regarding their daily lives, for instance, by implementing opportunities for participation (Dedding et al., 2013).

Participatory Peer Research. PPR is a method to allow clients in residential care institutions to regain self-control and perceive a feeling of mastery. In PPR clients function as participant-researchers of problems or developments that occur within their immediate social environment. An important characteristic of this peer research is that the clients are actively involved in various phases of the research process, such as composing a list of interview questions, interviewing, and discussing the consequences of the results. The clients actively and independently acquire information (Dedding et al., 2013; Hart, 1997). Clients have input in formulating topics, research questions, choice of methodology, data collection, presentation, and implementation and monitoring of the consequences of the results (Dedding et al., 2013). A democratic dialogue is developed, in which the imbalance in power between clients and supervisors can disappear (Hart, 1997; Sabo Flores, 2007).

A group of clients comes together to form a research group. Generally, clients living in institutional care have questions, points of interests, problems with their direct environment, or things they miss. This can be the starting point for the PPR project. With guidance of the PPR coach(es), the participant-researchers start with group brainstorming about topics they would like to change or create within the (routines in the) institution. Subsequently, the appropriate research method and research tools are chosen (a questionnaire, an interview, a focus group, etc.). Then, the client researchers

are involved in several aspects of the design of the research (e.g., composing questionnaires, communication with peers and professionals).

The client researchers are subsequently trained in (research) communication skills. Hereafter, it is defined and justified how respondents for the research project are selected, who will play a role in the selection procedure, and how the group of respondents is composed. During this process, the qualities and capacities of the client researchers are taken into account. It is assessed whether the client researchers know how to collect the data, how to handle the data recording, and how the coaches can support the client researchers during data collection. Based on the data collected, the client researchers, supported by the coaches, analyze the data, draw conclusions and formulate follow-up actions. The coaches (when asked for help by the client researchers) assist in the process of drawing correct and concrete conclusions. The next step is presenting and reporting results. Together, participant-researchers and coaches decide which form of presentation is appropriate to present the results. Finally, it is discussed which follow-up actions are needed. Specific attention is paid to the role of client researchers in the process of implementation of research results.

Present Study. The aim of this study was to evaluate the effects of PPR in young adults with MID and severe behavioral problems living in a residential care institution. It was hypothesized that PPR is associated with (1) an improvement in self-esteem, (2) a decrease in external locus of control, and (3) a decrease in self-serving cognitive distortions.

Method

Participants. The present study was conducted in a Dutch residential care institution for young adults with mild intellectual disabilities and severe behavioral problems. The study was designed as a multiple case study, with five respondents in the experimental group and five respondents in the comparison group. The mean age of the respondents was 21.4 years ($SD = 5.06$); and the mean length of stay in the institution was 31 months (range 1–160 months). All participants of both experimental and control group were male.

Procedure. Data were collected using questionnaires and conducting a semistructured interview, administered twice to the participants in both the experimental and the comparison group; before ($T = 0$) and after conducting the PPR project ($T = 1$) 3 months later. The interviews were conducted by a research master student. To guide these interviews, the following list of questions which were based on the levels of participation of Hart's ladder (1997) was used: (1) *are you allowed to state your opinion at your living group and job?*; (2) *do group workers enquire about your opinion?*; (3) *do group workers listen to your opinion?*; (4) *are group workers interested in your opinion?*; (5) *is something actually done with your opinion when you state it?*; (6) *do you know which subjects are being changed within the institution?*; (7)

are you able to say you would want something to change within the institution?; and 8) are you able to do something yourself to change the subjects within the institution?

All respondents participated voluntarily in the study, and were informed in advance about what it meant to participate in the study and the participatory project. They were told that their answers to the research questions would be treated confidentially and anonymously, and would be accessed only by the researchers. To compose an experimental and a comparison group, participants were asked to indicate in which group they would like to participate. Participants in the experimental group joined PPR and were trained as participant-researchers, whereas participants in the comparison group did not receive any additional training or guidance.

Intervention. A group of five clients collaborated with two coaches who supported the clients in conducting their research project. Two hour meetings with the clients and the coaches took place twice a week during a period of 3 months. Clients addressed four research subjects: leisure time, fire safety, client transportation, and communication between group workers and clients. The client researchers composed structured questionnaires, and interviewed twenty-three fellow clients to find out the importance of these subjects in the institution from a client perspective. Data were analyzed by the client researchers, with support from their coaches. Finally, results of the research project were presented to the management of the institute. The client researchers used an oral presentation and sung a rap song describing the main results of the research project.

Measures. Self-esteem of the client researchers was measured using the Rosenberg self-esteem scale (RSES; Rosenberg, 1965; Cronbach's α normative sample¹ = .87). The RSES is a 10-item scale, designed to represent a continuum of self-worth statements. For this study, the RSES was translated into Dutch and customized for use in individuals with mild intellectual disabilities by simplifying and shortening the statements of the questionnaire.

Locus of control was measured using a Dutch version of the Locus of Control Scale by Rotter (Pugh, 1994; Rotter, 1966; Cronbach's α normative sample = .72). This scale was customized for use in individuals with mild intellectual disabilities by simplifying and shortening the statements. The questionnaire consists of sixteen items (plus four filler items). Scores range from zero to 16, with higher scores indicating a more external locus of control.

Self-serving cognitive distortions were measured with the 54-item Dutch version of the *How I Think* (HIT) questionnaire (Nas et al., 2008) assessing four categories of self-serving cognitive distortions (thinking errors): self-centered (Cronbach's α normative sample = .76), blaming others (Cronbach's α normative sample = .77), minimizing/mislabeling (Cronbach's α normative sample = .78), and assuming the worst (Cronbach's α normative sample = .78).

Table 6.1. Pretest Scores, Posttest Scores, and Reliable Change Index (RCI) for Self-Esteem in the Experimental and Comparison Groups

| | Subject | Pretest | Posttest | RCI |
|---------------------|---------|---------|----------|--------|
| <i>Experimental</i> | 1 | 19 | 20 | .44 |
| | 2 | 33 | 37 | 1.75* |
| | 3 | 33 | 33 | 0 |
| | 4 | 28 | 30 | .88 |
| | 5 | 29 | 30 | .44 |
| <i>Comparison</i> | 6 | 21 | 22 | .44 |
| | 7 | 30 | 25 | -2.19× |
| | 8 | 33 | 34 | .44 |
| | 9 | 34 | 30 | -1.75 |
| | 10 | 19 | 22 | 1.31 |

Note: * $p < .05$ (one-tailed significance); × $p < .05$ (two-tailed significance)

Level of Participation. In addition to the questionnaires, all participants in both groups were interviewed before and after the project to verify their perceived pre- and post level of participation. By comparing these levels, it was assessed whether the participation level was successfully enlarged within the experimental group. The questions used were based on the eight levels of participation of Hart (1997), with increasing levels of involvement ranging from non-participation to full participation. Further, participants in the experimental group were asked how they valued participating in the project and about any changes they experienced after having finished the project.

Statistical Analysis. To examine individual changes over time, the Reliable Change Index (RCI; Jacobson & Truax, 1991) was used. Because improvement in self-esteem, external locus of control, and cognitive distortions were expected for individuals within the experimental group, one-tailed significance tests were conducted with an alpha confidence level of .05. An $RCI \geq 1.64$ indicated a significant improvement in scores. In the comparison group, two-tailed significance tests with an alpha-level of .05 were conducted, because there was no expected (direction of) change. In this group, a RCI of ≥ 1.96 or ≤ -1.96 indicated a significant change in scores (Jacobson & Truax, 1991).

Results

Changes in Self-Esteem, Locus of Control, and Thinking Errors. In Tables 6.1 and 6.2, the pretest scores, the posttest scores, and the RCI for self-esteem and locus of control of all participants are presented. In contrast to the expectations, only one of the participants in the experimental group showed a significant positive change in self-esteem and none of them changed significantly in their scores on locus of control. In the comparison group, one of the participants showed a significant deterioration in

Table 6.2. Pretest Scores, Posttest Scores, and Reliable Change Index (RCI) for Locus of Control in the Experimental and Comparison Groups

| | <i>Subject</i> | <i>Pretest</i> | <i>Posttest</i> | <i>RCI</i> |
|---------------------|----------------|----------------|-----------------|--------------------|
| <i>Experimental</i> | 1 | 6 | 8 | .80 |
| | 2 | 13 | 13 | 0 |
| | 3 | 12 | 12 | 0 |
| | 4 | 10 | 9 | -.40 |
| | 5 | 5 | 9 | 1.60 |
| <i>Comparison</i> | 6 | 8 | 6 | -.80 |
| | 7 | 10 | 12 | .80 |
| | 8 | 10 | 10 | 0 |
| | 9 | 13 | 8 | -2.00 [×] |
| | 10 | 9 | 8 | -.40 |

Note: * $p < .05$ (one-tailed significance); [×] $p < .05$ (two-tailed significance)

self-esteem, and another individual showed a significant deterioration in locus of control.

A majority of the participants in the experimental group showed significantly less self-serving cognitive distortions at posttest (see Table 6.3). Four of these participants showed significantly less self-centered thinking after 3 months of PPR, whereas one participant in the comparison group showed significantly more self-centered thinking at posttest. Similarly, four of the participants in the experimental group were significantly less inclined to blame others after their participation in the project, whereas none of the participants in the comparison group showed a significant change in blaming others. Three of the participants in the experimental group were significantly less inclined to show minimizing/mislabeled. However, in the comparison group one participant showed more minimizing/mislabeled, whereas the other showed less minimizing/mislabeled. At last, three of five participants in the experimental group were significantly less inclined to assume the worst, whereas in the comparison group, one of the participants was more inclined to assume the worst.

As can be derived from Table 6.3, none of the participants in the experimental group showed a deterioration in any of the self-serving types of cognitive distortions. All PPR clients showed improvement in distorted thinking. However, this improvement was not significant in all cases. In contrast, many of the participants in the comparison group did show a deterioration in distorted thinking. In some of these cases, this deterioration was significant.

Level of Participation. No substantial changes in the interaction between group workers and clients regarding the participants' possibilities to express their opinions were reported after the PPR project. Before the project took place, none of the participants were aware of management

Table 6.3. Pretest Scores, Posttest Scores, and Reliable Change Index (RCI) for Self-Serving Cognitive Distortions in the Experimental and Comparison Groups

| | | Pretest | Posttest | RCI | Pretest | Posttest | RCI |
|--------------|----|-------------------------------|----------|--------------------|---------------------------|----------|--------------------|
| Subject | | Self-Centred | | | Blaming Others | | |
| Experimental | 1 | 1.89 | 1.56 | .71 | 2.80 | 1.70 | 2.22** |
| | 2 | 2.56 | 1.33 | 2.65** | 2.60 | 1.30 | 2.63** |
| | 3 | 1.89 | 1.11 | 1.68* | 1.90 | 1.40 | 1.01 |
| | 4 | 3.33 | 2.33 | 2.15** | 3.30 | 1.90 | 2.83** |
| | 5 | 2.22 | 1.44 | 1.68** | 2.50 | 1.50 | 2.02** |
| Comparison | 6 | 2.22 | 2.44 | -.47 | 2.40 | 2.30 | .20 |
| | 7 | 1.22 | 1.11 | .24 | 2.60 | 2.30 | .61 |
| | 8 | 2.44 | 3 | -1.21 | 2.50 | 3.30 | -1.62 |
| | 9 | 1.44 | 2.67 | -2.65 ^x | 1.10 | 1.90 | -1.62 |
| | 10 | 1.78 | 1.78 | 0 | 1.50 | 1.60 | -.20 |
| | | <i>Minimizing/mislabeling</i> | | | <i>Assuming the Worst</i> | | |
| Experimental | 1 | 3.44 | 1.67 | 3.98** | 2.64 | 2.36 | .64 |
| | 2 | 2.00 | 1.44 | 1.26 | 2.91 | 1.64 | 2.90** |
| | 3 | 1.89 | 1.11 | 1.76* | 1.45 | 1.27 | .41 |
| | 4 | 2.56 | 1.67 | 2.00** | 3.36 | 2.18 | 2.70** |
| | 5 | 2.67 | 1.67 | 2.25** | 2.64 | 1.73 | 2.08** |
| Comparison | 6 | 2.44 | 2.44 | 0 | 3.09 | 2.27 | 1.87 |
| | 7 | 1.89 | 1.00 | 2.00 ^x | 2.00 | 1.36 | 1.46 |
| | 8 | 1.56 | 2.56 | -2.25 ^x | 2.09 | 3.09 | -2.28 ^x |
| | 9 | 1.56 | 2.33 | -1.73 | 1.36 | 2.18 | -1.87 |
| | 10 | 1.44 | 1.89 | -1.01 | 2.18 | 2.00 | .41 |

Note: * $p < .05$, ** $p < .025$ (one-tailed significance); ^x $p < .05$ (two-tailed significance)

issues and policy changes within the institution. However, after the project all participants in the experimental group were aware of some upcoming changes. At post-test, participants in the experimental group felt more able to express which aspects in the institution needed to change. Moreover, they now believed it was useful to say what they would like to be changed, and that they felt able to initiate changes themselves. No substantial changes in their involvement in institutional policy developments were reported by the participants in the comparison group. In short, participants' perceptions of their involvement in changes within the institution improved after participation in the PPR project. However, involvement was still limited to subjects that were discussed within the PPR project.

Experiences of the Client Researchers. Some of the client researchers indicated that it was difficult for them to work on different subjects and tasks at the same time, and that some tasks were quite difficult for them. Besides, the client researchers mentioned that the collaboration with other clients with MID sometimes proved to be difficult. All participants

appreciated their mutual collaboration and interaction with their coaches and having the opportunity to represent the interests of other clients. They also thought the project was informative and challenged them to become active and aware and responsible for their own situation. Besides, the participants appreciated the mutual trust and the way clients communicated with each other. Finally, the client researchers stated that they had acquired several communication skills, like conducting calm conversations, listening to others' opinions, and allowing others to finish their sentence.

Discussion

In this study, the application of PPR involving young adults with MID and severe behavioral problems living in a residential care institution was examined to explore its viability as both a research tool and intervention. The current study, although based on a small sample, shows that this method allows for relatively fast implementation of results. In the current example, PPR was not associated with gaining more self-esteem and less external locus of control in the participants. A possible explanation for not finding a significantly improved self-esteem is that it generally takes a long time to change one's level of self-esteem, because self-esteem reflects people's representations of how they typically feel about themselves across time and context.

The finding that external locus of control had not decreased after participation in the PPR project may be explained by the fact that the participants received frequent feedback within the context of the PPR project, but not in other contexts, they participated in, such as the living group and their working place. In these other contexts, the level of participation had not changed. However, we did find that most individuals who joined the PPR project showed a significant decrease in self-serving cognitive distortions. It is possible that positive changes in cognitive distortions precede changes in self-esteem and locus of control, which would explain lack of changes in self-esteem and locus of control, because it simply takes more time before improved cognitive functioning affects self-esteem and locus of control.

Results showed no substantial changes in the interaction between clients and their group workers and in clients' possibilities to express their opinion after participating in the PPR project. This may be due to the fact that the PPR project was still a rather isolated project within the institution, and this way of thinking about and working with clients' abilities had not penetrated in other areas of the clients' institutional life. Nevertheless, participants' perceptions of their involvement in changes at stake within the institution improved after introduction of PPR. The participants who participated in PPR knew about changing institute policies, felt they could indicate what they wanted to change, and could initiate changes within

the institution themselves. In contrast, no substantial changes in the actual involvement in policy developments within the institution were reported by the participants in the comparison group.

The participants in the comparison group did show significant changes in some of the outcome measures (e.g., external locus of control and some of the cognitive distortions). However, most of these changes were in a negative direction. These findings could indicate a buffer effect of PPR. In residential care, individuals often experience a lack of frequent feedback and control, because staff responsiveness to the needs of the clients is often insufficient, and the living group climate is often characterized by repressive control (Knotter et al., 2013). Therefore, a decrease in self-esteem and an increase in external locus of control and cognitive distortions may be expected if nothing is done to counteract these negative changes (Van der Helm et al., 2014).

There are some limitations of this study that need to be acknowledged. First, participants were not randomly assigned to the experimental or comparison group. Therefore, it cannot be ruled out that differences in results were caused by unmeasured factors (e.g., differences in group climate). Notably, insufficient statistical power did not allow testing possible pre-existing differences in outcome variables or background characteristics between the experimental and control group. Second, two questionnaires were customized for use with individuals with MID, which may have had consequences for the validity and reliability of these instruments. Third, the period between the pretest and posttest was only 3 months, which is a rather short period to implement PPR in all relevant aspects of living and working in an institution. For future research, it is recommended to pay attention to the level of participation in all aspects of a client's life in an institution, such as the group climate, leisure time, and daytime activities. To achieve this, it is recommended to prolong the period of a PPR project, or even better, to institutionalize PPR, and use research results of PPR projects as a constant source for the improvement of living circumstances, communication between clients and staff and management (Dedding et al., 2013). In that way, the probability of achieving significant positive changes in participants' self-esteem, locus of control, and self-serving cognitive distortions may be enlarged. Fourth, both groups were too small in order to generalize results and gain sufficient statistical power to establish significant differences between the experimental and comparison group. For future research, it is recommended to use larger sample sizes.

Despite these limitations, the results of this study illustrate that positive changes in young adults with MID involved in PPR may occur. There are some important implications for practice. First, this study indicates that providing frequent adequate feedback and restoring control could be important components in daily care routines of individuals with MID. By providing clients with extended control and frequent social

feedback by means of PPR, self-serving cognitive distortions, and possibly later challenging behavior, may be mitigated (e.g., Langdon, Daniel, & Sadek, 2016). Second, the results fit with the recent trend in research on intellectual disabilities, which focuses on an individuals' capacities rather than on their limitations (e.g., Schalock, 2017). Even though client participants were novices in working together in a PPR project generally they proved capable of executing research. Furthermore, although it did not lead to an increase in self-esteem (yet), the client researchers indicated they felt strengthened because they were taken seriously, were able to represent the interests of other clients, and could initiate change themselves.

The present study was the first Dutch study to evaluate PPR in young adults with MID. PPR may compensate for a lack of adequate feedback and control by implementing opportunities for participation, and in turn may diminish distorted thinking and problem behavior in young individuals with MID. Future research should focus on the effectiveness of PPR using larger samples and random allocation to experimental and control groups to provide proof of the effects of PPR. The present study shows promising first results, and demonstrates that the application of PPR is feasible under clinically representative conditions.

Our elaborate example of PPR does not demonstrate effectiveness in a regular statistical way by ruling out alternative explanations for the established effects, but provides clients with a tool to change their social environment and life circumstances by conducting research themselves. The PPR model allows clients to guide and experience their own process of change, enabling immediate implementation of research results. This is especially important in individuals whose needs for self-determination (contact, competence, and autonomy; Ryan & Deci, 2000) may be compromised, such as in young adults with MID and severe behavioral and psychiatric problems in residential care (e.g., Burke et al., 2018; Ditchman, Kosyluk, Lee, & Jones, 2016; Shogren, Wehmeyer, Palmer, Rifenshark, & Little, 2015; Shogren, Wehmeyer, Schalock, & Thompson, 2017). Although the PPR design is the weakest design from the perspective of robust experimental control, it is the best design from the perspective of client participation and fast implementation of study outcomes, empowering clients with MID to take more control over their life. PPR might even be combined with RCTs, or alternatives to RCT with a similar evidential value, ruling out alternative explanations for the positive effects of PPR.

To conclude, although we certainly do not question the value of RCTs as the golden standard for effectiveness research, we believe science should also provide clinical practice with research methods that yield faster answers to urgent questions, maximizing the role of clients as active participants in research and the most important stakeholders. One way to do so, and to bridge the gap between science and practice, can be found in PPR, where clients conduct the research themselves.

Note

1. Unfortunately, our total sample size of $N = 10$ was not sufficient to calculate alphas for the study sample

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