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While involving children and youth with disability as research partners was viewed positively, methodologically strong research is required to further inform effective participation and outcomes

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Synopsis

Summary of: Bailey, S., Boddy, K., Briscoe, S. & Morris, C. (2014). Involving disabled children and young people as partners in research: A systematic review. *Child: Care, Health & Development*, *41*(4), 505-514. doi: 10.1111/cch.12197.

Objectives of the review: To explore how children and youth with disabilities (CYD) have been involved in research; how the practicalities and challenges of their involvement have been managed; and to describe the impact of involvement on both the CYD and the research.

Design: Systematic review

Search strategies: Searches for English-language studies published since 1990 were conducted in MEDLINE, CINAHL, ProQuest and Cochrane Databases. Included studies were peer reviewed papers of studies of any design, reports, guidelines and grey literature that reported participation of CYD in research.

Selection criteria: The Equality and Human Rights Commission definition of disability guided study selection.

Methods of review: The review team included six parents of CYD as well as professionals. Independent screening of titles, abstracts (n = 2,495) and full texts (n = 61) by two authors was performed. Data were extracted by one reviewer, checked by another. Study quality was appraised using a modified Critical Appraisal Skills Program qualitative checklist although no study was excluded based on quality. A narrative summary of findings was produced. AMSTAR: Points assigned for *a priori*

design; independent selection and extraction; comprehensive search; inclusive of publication types; characteristics of included studies described; study quality assessed; quality used in formulating conclusions.

Results: Twenty-two included documents were reviews ($n = 7$), original research ($n = 8$), reports ($n = 3$), guidelines ($n = 3$), and one webpage. Four documents had been produced in partnership with CYD and two reported research about involvement of CYD. Quality of the included documents was deemed to be low, with few providing sufficient detail about CYD involvement. Nine documents describing involvement of CYD (aged 10-21years) provided data to address the three objectives: 1) *Involvement of CYD* - was sought through advertising, volunteering and via parents and partner organisations. Clear, appropriately written explanations about what CYD are being asked to do was recommended. 2) *Solving the practicalities of involvement* included meeting CYD access and communication needs; balancing rights and responsibilities of involvement without over-burdening or distressing CYD; and working with potential gatekeepers to manage inclusion of CYD perspectives. 3) *Impact of involvement* on CYD were potentially positive (e.g., increased confidence, being empowered, greater responsibility) and negative (e.g., potential distress related to learning about other's perspectives and experiences, difficulties maintaining confidentiality, perceptions of tokenism). Positive impact on the research process included improved quality, greater acceptability of the research to CYD and greater credibility. Potential negative research impacts included increased resource needs, including time, to effectively include CYD.

Authors' conclusions: Although several examples of successful involvement of CYD in research were located, the quality of reporting was generally low. Further methodological research is required to inform appropriate approaches to their effective and successful inclusion in research.

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Commentary

Involving children and young people with disabilities in research is an important objective for many, including occupational therapy researchers. The shift towards including the voices of those with disabilities (Hurst, 2003) in the research process aims to counterbalance potential hierarchical and exploitative aspects of the research relationships (Hammell, 2006). Bailey and colleagues (2014) explore how researchers have worked in partnership with this population. They argue that the 22 included studies present some concerns with respect to the quality of evidence and reporting of results. There are; however, a few key themes arising from the review requiring consideration when designing research methodology and building partnerships for working with young people. First, the authors raise the consideration of gatekeepers, who may include or exclude individuals from partnerships through lack of communication about participation opportunities. Second, and arguably most important in clinical and research settings advocating client centred practice, is the belief of gatekeepers about who is most capable of participating. This included a concern that those without parents to advocate for them may be excluded.

Although this review is constrained by a low level of evidence, thereby limiting the ability of the findings to be further translated into guidelines, there is an important recognition that flexibility must be a part of the research process. Providing children and youth with the opportunity to decide how they want to be involved in the research process may increase opportunities for partnership. This approach is consistent with client-centred occupational therapy practice. However, more research is required to determine the effectiveness of such partnerships. In particular, research about how to incorporate flexibility into research designs is needed because rigid designs may inadvertently uphold power relationships (Hammell, 2006), which may minimise the impact of research findings in the lives of youth and their families.

Lack of clarity regarding the role of children and young people with disabilities in the review was a concern, given the topic. The authors' state parent involvement in the study was high and guided the scope of the review; however, it is not clear how this took place. Adolescents with disabilities may continue relying on their parents for support, but like their nondisabled peers begin to assert their own autonomy and unique perspectives (Beresford, 2004), that must be considered when designing family centred research. Nevertheless, the central finding of this review, that partnerships should include an evaluation of positive and negative outcomes for both the research process and individual participants should be accounted for by occupational therapy researchers.

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