Keywords: dependence, empowerment, disability, decision-making, collaborative problem solving

Background
Many individuals with disabilities allow others to do things for them rather than taking an active role in making decisions about their lives. This is because caregivers often take the lead as part of their caregiving role, which prevents individuals with disabilities taking a leadership role in their own lives.

There are many negative consequences to limiting decision-making opportunities in the lives of individuals with disabilities. Common practice in social care ranges from excluding those who need support to actively harming them. These practices restrict and neglect the capacities of individuals with disabilities (Finlay, Walton, & Antaki, 2008). People with disabilities have reported how big decisions are out of their own control. These are decisions that can impact both long term and day-to-day life. For example, decisions about residences, roommates, finances, and daily routines may be withheld (Treece, Gregory, & Ayres, 2010).

Giving individuals with disabilities the chance to practice leading the problem solving process is one way to empower them to lead positive change in their lives. As one individual with a disability from our support organization said “Give us a voice to make changes and improvements. Let us tell you what we like and what we don’t like. Sometimes we know how to solve our problems if you ask us.”

Recent research has found that including individuals with disabilities in the management of their own complex needs has the potential to improve the types of support services they receive and their ultimate outcomes (Connor & Ferri, 2007; Clare & Cox, 2003). One study found that when families and support systems make all the decisions, it makes it harder for the individuals with disabilities to be heard and understood (Bjarnson, 2002). This is because it shifts advocacy, responsibility, and self determination away from individuals with disabilities, while enforcing a dependence model of support. However, there is little research that gives concrete steps about how to better involve individuals with disabilities in the decision making process. One study showed that young men with physical disabilities excluded from previous peer groups felt empowered when they were given the opportunity to take a leadership role in solving their own problems within their peer group (Hernandez & Brigida, 2005).

Objectives
The objective was to evaluate a workshop where individuals with disabilities and their caregivers (support staff, residential caregivers, and family members) are taught about collaborative problem solving and given the opportunity to experience and apply collaborative problem-solving concepts.

Method
Participants were recruited through local disabilities support agencies (Calgary, Alberta and surrounding area). Ninety people registered for three workshop sessions of thirty people each. All participants were in existing pairs of caregiver and individual with disabilities. The workshop materials were initially piloted with twelve participants. The purpose of this was to find out whether participants understood the workshop material and questionnaire before the full workshops were held. Based on the feedback we received, the questionnaire was reworded to prevent bias and maintain respect.

We delivered the workshop about collaborative problem solving for individuals with disabilities and their caregivers. Participants learned about how systems of rewards and punishments do not work for most people. With collaborative problem solving, individuals with disabilities are empowered to assume
decision making and leadership roles in solving their own problems. Caregivers learned to help empower individuals with disabilities rather than continuing to enforce a culture of dependency.

We used a qualitative evaluation approach by asking open-ended questions of workshop participants before and after the workshop. Participants were divided into the following four groups: daytime caregivers, residential caregivers, family members, and individuals with disabilities. We wanted to find out whether individuals with disabilities and their caregivers would apply collaborative problem solving techniques learned in the workshop to promote independence and leadership among individuals with disabilities. Individuals with disabilities had the questions read to them by a research assistant who then recorded their answers. Responses were grouped into common themes which were then analyzed.

Results

Daytime caregivers and individuals with disabilities had high response rates to the questionnaire with over 80% completing the questionnaire before the workshop and 50% completing the questionnaire after the workshop. However, few residential caregivers or family members responded to the surveys, so their results were not included in the analysis.

The following is a summary of some of the main findings after the workshop:

- Daytime caregivers were more likely to think that day to day activities, like food and clothing choices, were the responsibility of the individual with a disability. Participants with disabilities also agreed with this after the workshop.
- Daytime caregivers were more likely to think that individuals with disabilities should be responsible for choosing the following:
  - participation in cleaning and other household chores
  - community participation
  - friends and social involvement
- Daytime caregivers said they were more likely to have discussions with individuals with disabilities to come up with solutions to problems together.
- Both daytime caregivers and individuals with disabilities responded that caregivers should be responsible for leading problem-solving discussions.
- Daytime caregivers were more likely to think that individuals with disabilities are responsible for final decision-making for problems. However, when asked who actually makes the final decisions, over half of participants with disabilities said their caregivers did. This did not change after the workshop.

The results of this workshop suggest a change in attitudes of daytime caregivers and individuals with disabilities, with a positive shift toward encouraging the independence of individuals with disabilities. We were unable to determine effectiveness of training with residential caregivers or family members as they did not complete the questionnaire.

Conclusions

It has been easier and more comfortable for individuals with disabilities to be compliant and their caregivers to fall into a role of looking after, rather than supporting independence. Training in collaborative problem solving has been shown to encourage individuals with disabilities to exercise control over their own lives, while daytime caregivers learn to adopt a new, more supportive role.

Lessons Learned

In this research project, we learned the importance of involving individuals with disabilities in helping to solve their own problems. However, we also found it was quite difficult to get both individuals with disabilities and their caregivers out of a mindset of relying on caregivers to lead problem solving. We found that caregivers providing support during the day and individuals with disabilities were successfully able to work on solving problems together. However, we also found it challenging to engage family members and residential caregivers (who spend the most time with individuals with disabilities) to participate in research or redefining problem solving. This may be because they are entrenched in established perceptions about the roles of caregivers and individuals with disabilities.
We also learned the importance of having a strong research team to actively encourage participants to speak up in 'small' settings. While conducting our research, we faced some challenges in retaining a strong research team to complete data collection and analysis of results.

It remains unclear whether our workshops will have a lasting effect on empowering individuals with disabilities. We were unable to evaluate whether the collaborative problem solving workshop was effective at helping residential caregivers or family members work together with people with disabilities because these participants chose not to complete our evaluation surveys. We also learned that some staff and individuals with disabilities had difficulty understanding the survey questions even though we made revisions based on pilot testing. In future, using multiple choice instead of open-ended questions may be more successful because it may make participation easier, and therefore increase the number of questionnaires completed.

The full report can be found at www.mentalhealthresearch.ca

References


About the Author: Adam Heighes (Vantage Enterprises Ltd.) has a BA in Psychology and Sociology, a post graduate diploma in Inclusive Education, and an MA in Integrated Studies specializing in Community Development and Education. His studies have focused on the inclusion of individuals with disabilities and marginalized groups in the greater community. He is also a parent of adult children with disabilities, and has spent a lifetime advocating for friends and relatives marginalized by society. In his professional life, Adam has worked for more than 22 years in disability services, education, and mental health in a variety of areas including advocacy, day and residential support, teaching, and day and residential program management. Adam has also served in several volunteer capacities supporting marginalized groups (individuals with disabilities, children, and the poor) in Alberta and Ontario. He has been a member of several organizations, including the Learning Disabilities Association, Calgary Learning Centre, parent and staff advisory groups, and school boards.