

BRIEF REPORT: Caregiver Versus Self-Reported Views on What is Important to Clients With Intellectual Disability

Abstract

Using data from preliminary research on the use of the new service application package in Ontario, caregiver and client perspectives on what is important in the lives of adults with intellectual disabilities were examined. A qualitative analysis of the differences between what is important to individuals with intellectual disability and what others think is important for them was conducted for a sample of 92 individuals and their caregivers. When responses of the two groups were compared, no agreement was found for 44% of the cases. Some agreement was found for 39% of the cases and strong agreement was found for 17% of client/caregiver dyads. The priority areas of the two groups differed, with clients prioritizing Family and Friends and Recreational Activities and caregivers prioritizing Health and Safety and Self-Determination.

Introduction

In clinical and research environments, there are various ways of attaining information on individuals with intellectual disability (ID). Parents, caregivers, staff, and the individuals themselves have all been used in a variety of settings as sources of information. To try and best meet the needs of individuals with ID it is important to ask questions of them as well as their natural supports. Self-report and involvement of the individual in service planning are essential, as they allow participants to have the opportunity to express their private desires, emotions, and needs.

Ontario is moving towards a model of service allocation driven by client needs for service and supports that utilizes information from caregivers as well as information from individuals with ID (Ontario Ministry of Community and Social Services, 2006). This format follows person-centered planning, a process that involves creating a plan and personal vision for those with developmental disability (Northeast Alberta Community Board Persons with Developmental Disabilities, 2005). The individual as well as family members and staff can contribute to discussion, in which the goal is to learn about the individual so that services and supports are tailored to the individual's needs.

The objective of this study was to analyze the differences between caregivers and individuals with ID in terms of what they regard as important in the life of the individual with ID. We were interested in knowing how responses differ, and which response categories achieved the highest level of agreement.

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Method

Data from this study were derived from the Ontario Ministry of Community and Social Services Application Package for Developmental Services Pilot Project. This study was approved by the Centre for Addiction and Mental Health research ethics board. In this project, individuals with ID were interviewed with their caregivers about their current services, their support needs, and their satisfaction with their current situation. The individual, together with his or her caregivers, was also asked a series of open ended questions about matters most important to him/her. Each group was interviewed by trained interviewers using set questions and all responses were written down/recorded by the interviewer.

For this study, data from two of the questions from within the "Getting to know you" (GTKY) section were analyzed using a thematic analysis approach. The GTKY section is part of the larger disability service application package in Ontario, and is intended to provide relevant personal information and engage the client in the application process. The two questions asked in the interview and being analyzed for this study were: "What is important to me" as well as "What others think is important to me."

Participants

Through random selection, information from 100 caregiver-individual dyads was reviewed from a total of 479 who participated in a pilot of the application package. The findings presented below are based on only 92 dyads, due to 8 dyads in which only one (caregiver or individual with ID) responded. The mean age of the sample was 40.7 years ($SD = 14.9$). Four percent could not understand spoken language, 52% could moderately understand it, and 44% could understand it very well.

Analysis

A qualitative analysis of the specific differences in items mentioned was then conducted. Across participants, a total of 411 responses were provided to the question "This is important to me" and 338 responses to "Others think this is important to me." Through an inductive process, a coding scheme was created and

responses to the questions were categorized into the following categories: *Health and Safety*, *Career, Financial and Material*, *Family and Friends*, *Self-Determination*, *Recreational Activities*, *Helping Others*, *Residence*, *Routine*, and *Day Program*. The response categories provided by the two groups were then compared.

Dyad responses to "What is important to me" as well as "What others think is important to me" were also compared for similarities and differences. Response pairs were rated as having no agreement, some agreement, or strong agreement, depending on the similarities in categories and items mentioned.

Results

Categorically, responses to the two questions provided different information (see Table 1). The priority areas of the two groups differed, with individuals with ID prioritizing *Family and Friends* and *Recreational Activities* and caregivers prioritizing *Health and Safety* and *Self-Determination*. The largest discrepancy between reports was on *Health and Safety* as well as on *Family and Friends*.

When responses to the two questions were compared, no agreement was found for 44% of the cases. Some agreement was found for 39% of the cases and strong agreement was found for 17% of individual/caregiver dyads.

Discussion

The current study found that the categories "This is important to me" and "Others think this is important for me" provided different information, indicating that there are differences in what caregivers identify as important for the person with a disability, and what that person believes is important for him or herself. The differences in priority areas may be due to differing focuses that exist for individual and caregivers as to what is necessary for their well-being, with caregivers' concerns lying within the realm of long-term safety. Previous research looking at the quality of life in individuals with ID has demonstrated that an emphasis is placed on social contact and activities (Miller, Cooper, Cook, & Petch, 2008), findings very similar to

Table 1. Category percentages for "Others think this is important for me" and "This is important to me"

| | <i>Others think this is important to me</i> | | <i>This is important to me</i> | |
|-------------------------|---|--------------|--------------------------------|--------------|
| | <i>n (%)</i> | | <i>n (%)</i> | |
| Family and Friends | 63 | (18.5) | 157 | (38) |
| Recreational Activities | 37 | (11) | 69 | (17) |
| Self-Determination | 66 | (19.5) | 39 | (9.5) |
| Health and Safety | 82 | (24) | 19 | (4.5) |
| Financial/material | 17 | (5) | 55 | (13) |
| Residence | 25 | (7) | 31 | (7.5) |
| Routine | 26 | (8) | 15 | (3.5) |
| Career | 5 | (1.5) | 15 | (4) |
| Day Program | 9 | (3) | 7 | (2) |
| Helping Others | 8 | (2.5) | 4 | (1) |
| Total | 338 | (100) | 411 | (100) |

those found in the current study. Individuals with ID are motivated for a variety of reasons to obtain social contact, such as guidance, positive interactions, and emotional support (for a review on interpersonal research, see Lunsky, 2006).

This study has a number of limitations worth noting. The data used in this study were collected for alternative purposes; therefore, information on some important variables is unavailable. The data used in this study were collected as part of a pilot evaluation of the developmental services application package, and not specifically for research purposes and so certain relevant details on the interviews are absent. For example, interviewers were instructed to record what was said in the interviews but not who made each comment. Thus, we cannot examine how much caregivers assisted clients in giving their responses. In addition, the different styles employed by interviewers may have had an effect upon the responses.

This study demonstrates the importance of obtaining a variety of perspectives when determining priority needs and interests of individuals with ID. Given that perspectives differ, clinical decision making based on a single perspective should be discouraged. Future research should examine why there are differences and how to build a consensus

on life perspectives. The act of encouraging people with disabilities and caregivers to share their perspectives in a structured setting with an outside person might be beneficial. This sharing of information offers a more personal view of the individual's preferences, and can help service providers determine certain ways to execute services that allow inclusion, positive experiences, and the fostering of relationships. It can assist in tailoring services to the individual needs and preferences of service users, while concurrently fostering feelings of self-determination in the individual with ID by allowing them to contribute to their own plan. It may specifically remind service providers to continue to foster relationships and leisure, in addition to prioritizing independence and safety.

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