"I Can Speak for Myself": Involving Individuals With Intellectual Disabilities As Research Participants

Jennifer B. Mactavish, Michael J. Mahon, and Zana Marie Lutifiya

Abstract: The Lifespan and Disability Project, a 2-year qualitative study, was designed to enhance understanding of social integration by including the perspectives of individuals with intellectual disabilities. Procedures and strategies employed to involve these individuals in the project were documented. Specifically, we describe the use of individual interviews and focus groups (e.g., purpose, rationale, facilitation techniques) to collect data, and verification meetings in which a prompting hierarchy and curing were employed to assist participants in confirming or disconfirming the researchers' interpretations of the emerging findings. Highlights of the results were presented to illustrate the efficacy of the strategies in enabling the participants with intellectual disabilities to share their perspectives on social integration.

In previous literature on socially constructed concepts, such as social integration and quality of life, investigators have acknowledged the importance of including perspectives of individuals with intellectual disabilities (Good, 1988; Rosen, Simon, & McKinsey, 1995; Taylor & Bogdan, 1998). To date, however, research of this nature remains limited, which can be attributed, at least in part, to continuing debates about the most effective means of including people with intellectual disabilities in the research process and ensuring the credibility of researchers' interpretations of the information provided by these individuals (see, for example, Biklen & Moseley, 1988; Dattillo, Hage, & Malley, 1996; Sigelman et al., 1983). Building on this debate, in the present paper we have described the methods and procedures used in a qualitative study—the Lifespan and Disability Project—that was designed, among other aims, to enhance our understanding of social integration by examining the viewpoints of individuals with intellectual disabilities.

Review of Related Literature

Over the years, a number of recommendations have been made in the literature on useful approaches for involving individuals with intellectual disabilities in the research process and for enhancing the credibility of researchers' interpretations of their perspectives. Among the most commonly cited strategies are preparing the credibility and inherent value of all perspectives, collecting data in multiple and intensive ways over prolonged periods of time, and using concrete processes to elicit and confirm data. Presumption of credibility. Some researchers consciously begin with the assumption that all perspectives on an issue are correct and inherently valuable and equally useful (Ferguson, Ferguson, & Taylor, 1992; Taylor, Bogdan, & Lutfiya, 1995). In addition, these researchers insist on documenting the perspectives of individuals or groups typically excluded from the research process. Qualitative and feminist researchers, among others, have long subscribed to this point of view (Bogdan, 1998; Suttie, 1987; Sutcliffe, 1994). It must be prepared to cede, when needed (Aiken, 1988), to the researcher to inco- and support, howe the assumption that per- to the researchers' to integrate and supple- 

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ing research. It places an obligation on the
researchers to actively seek out, document, and
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als who may have been seen in other contexts
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cedures, when necessary, to enable participation
(Biklen & Moseley, 1988). The willingness of
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Multiple and intensive data-collection strate-
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data from individuals with intellectual disabilities
(Bercovici, 1983; Bogdan & Biklen, 1991;
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1983). For example, although standardized open-ended interviews are often rich sources of
data, this strategy according to Biklen and Moseley (1988), may prove to be "more confus-
ing than clarifying" (p. 158) when employed with
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Dattilo et al. (1996) described a series of
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posed that the same aims could be achieved by breaking open-ended questions into several concrete parts.

In summary, investigators have acknowledged that the perspectives of individuals with intellectual disabilities are imperative to research on socially constructed contexts (e.g., social integration, quality of life) that we subject to multiple interpretations (Bilker & Breen, 1986; Coote, 1988; Rosen et al., 1995; Taylor & Bogdan, 1998). A number of recommendations (presumption of credibility, qualitative research methods, concrete data-collection strategies) for including these individuals in the research process have been made to enact this imperative. Building on these recommendations, in this paper we describe the data-collection strategies, the process for implementing these strategies, and the approaches for ensuring the credibility of our interpretations of the participants' perspectives.

Setting the Context

Lifespan and Disability Research Project

Conducted over 2 years, the Lifespan and Disability Project involved a team of researchers from a number of disciplines (e.g., leisure sciences, education, sociology, gerontology, and family studies) and a network of community partners (e.g., service providers, caregivers, policymakers). Most members of this team had substantial experience working and interacting with individuals who have intellectual disabilities across a variety of settings (e.g., direct support/service delivery, research).

Our aim in this project was to develop a lifespan model of social integration that reflected the perspectives of individuals with intellectual disabilities. Grounded in a qualitative framework, we used multiple strategies to collect information and to confirm, with the participants, how well the emerging findings reflected their views on social integration.

Participants

Prospective participants were identified through nominations by representatives of community agencies (e.g., advocacy groups, service providers), who were partners in the Lifespan and Disability Project. They nominated people they thought would be interested and willing to take part in the research. A member of the research team made personal contact with each of the nominees (and in some cases their parents or legal guardians) and invited them to participate.

This process resulted in a sample of 32 individuals (18 females, 14 males), who ranged in age from 17 to 82 years (mean = 39.94, standard deviation = 20.9). Information provided by caregivers and/or the nominating agencies indicated that 14 of the participants had a mild, 10, a moderate, and 8, a severe, to profound level of disability. The group was drawn evenly, from a large urban center in Western Canada and a collection of small towns and rural settings. With the exception of one man in his early 30s who lived in a group home, all of the urban residents under age 35 lived at home with their biological families. Among rural residents of the same age group (17 to 34 years), 2 individuals lived at home with their biological families, and others resided in a variety of community living situations (i.e., independent apartment with a roommate, foster family, and group home). Beyond age 35, individuals' places of residence included group homes, foster families, and, in the case of 2 of the oldest participants, nursing homes. Most of the participants over age 35, however, were supported in independent apartments, typically with at least one roommate who also had a disability.

Excluding 4 of the oldest participants, who described themselves as "seized," all of these individuals were involved in day time activities that took them out of their homes. For the younger participants, attending school consumed most of the day. All of the urban participants attended the same high school, where their days were spent in integrated classes and work experience programs in the community. Their rural counterparts were high school students who split time each day between a segregated classroom and community work experience. Within each of these groups, although the participants were familiar with one another, they seldom, if ever, spent time together outside of school (e.g., engaging in common activities). Most of the 22- to 59-year-olds were employed in sheltered workshops, whereas a small group attended formal day programs or were engaged in volunteer activities in the community. Of the participants over age 60 who were not retired, 2 continued to work full-time in sheltered workshops, 1 worked part-time in a workshop as part of a recertification transition.

The Lifespan model included multiple steps: sorting, use 1). In the following strategies, the ratio implementation of...
process, and 1 volunteered in a nursing/home for older adults without disabilities. Unlike the participants who attended school, most of the adult participants did not know one another prior to the project, and, if they did, their contact with one another involved, as one man said, "seeing one another around, but we aren't really friends or anything."

Strategies and Processes for Involving Participants With Intellectual Disabilities

The Lifespan and Disability Project included multiple data-collection strategies that served distinct, yet interrelated, purposes (see Figure 1). In the following sections we describe these strategies, the rationale for their selection, and the implementation and verification procedures.

![Figure 1. Overview of data-collection strategies, implementation of strategies, and verification of interpretations](image)

**Data-Collection Strategies: Description and Rationale**

Our primary data-collection strategies were qualitative interviews and focus groups. Three basic types of qualitative interviews are described in the literature: (a) the informal conversational interview, (b) the standardized open-ended interview, and (c) the interview guide approach ( Merriman, 1988; Patton, 1990; Taylor & Bogdan, 1998). The informal conversational interview relies on questions that arise spontaneously from the natural interactions of the interviewer and the interviewee. Typically, this strategy is used in conjunction with participant observation and often takes place without the participant realizing that they are engaging in an interview (Patton, 1990). In a standardized open-ended interview, the technique most commonly used in previous research involving individuals with intellectual disabilities, the interviewer rigidly adheres to a fixed set of carefully worded questions that are asked in sequence (Malik et al., 1995; Sigelman et al., 1983). This approach affords little flexibility and is most often used when multiple interviewers are involved in data-collection (Merriman, 1988). An interview guide approach involves outlining, prior to the interviews, a series of issues and related questions to be explored. The sequencing and wording of questions emerges within the context of the interview, which creates relaxed and conversational interactions between the interviewer and interviewee.

In a conscious effort to foster this type of interaction, we used the interview guide approach for collecting background information (e.g., age, living arrangement, work/school) specific to each participant. More importantly, we selected and designed this approach as a means of (a) introducing the participants to a member of the research team, (b) establishing a basis for building rapport, and (c) explaining the research and subsequent data-collection procedures (focus groups).

The second strategy for collecting information in the Lifespan and Disability Project involved the use of focus groups. Krueger (1994) conceptualized this technique as "a carefully planned discussion designed to obtain perceptions on a defined area of interest in a permissive, and non-threatening environment" (p. 6).

In other words, a focus group is a group interview in which a small gathering of people discuss a topic or topics introduced by the researcher (Morgan, 1998). Discussions are usually facilitated using either a topic guide or questioning roux (Krueger, 1998). A topic guide is simply a list of words or phrases that reminds the researcher of key issues to be explored dur-

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ing the focus group. In contrast, a questioning route is a sequential series of questions, written in complete, conversational sentences. These questions are scripted in advance and routinely include six different types of questions: opening, introductory, transition, key, summary, and closing (see Table 1 for examples of each type of question) (Krueger, 1998). A questioning route is generally recommended when inconsistencies in wording may alter the intent or people’s interpretations of the questions (Krueger, 1998).

Focus groups, particularly those in which questioning routes are used, often are difficult to distinguish from other types of group interviews (e.g., nominal, Delphi). Focus groups and other approaches to group interviews differ, however, in that focus groups produce group data through discussion, whereas individual interviews generate data based on individual responses to questions asked in group settings (i.e., group data vs. individual data). Focus groups also are distinct in that the aim is not to reach consensus, arrive at mutually agreeable decisions, or decide on a single course of action (Krueger, 1994). Instead, focus groups are intended as a "way of listening to people and learning from them" (Morgan, 1998, p. 9) about their perceptions and feelings on a particular topic.

Although used effectively with audiences in different cultural and socioeconomic contexts and with groups from widely divergent educational backgrounds (Krueger, 1994), focus groups—at least in the way Krueger as well as Morgan (1998) described them—have been employed infrequently in published reports of studies that include people with intellectual disabilities. If the advantages attributed to this approach are considered, however, it appears that focus groups would be effective for learning about the perspectives of these individuals. Adding to this contention, Morgan noted that focus groups are used most appropriately in studies in which investigators examine diverse perspectives on complex behaviors and issues. Morgan described focus groups as "a particularly desirable research method" (p. 57) when there is a gap between people (e.g., professionals whose understanding of issues may be eternally different than those of the individuals they work with) and a friendly, respectful approach to research is required.

The advantages attributed to focus groups and Morgan’s (1998) points about appropriate uses of this method were the basis of our rationale for using focus groups to collect perspectives on social integration. We employed a questioning route for facilitating these groups to (a) ensure that the questions were worded conversationally yet concrete enough to elicit responses, (b) provide opportunities for seeking clarification, and (c) standardize the questions that were asked in each focus group (i.e., minimize potential variations that could be attributed to the way the questions were worded).

Process for Implementing the Data-Collection Strategies

Reflecting the distinct aims of their use, the interviews for focus groups were situated in a sequential, two-step data-collection process (see Figure 1): interviewing and focus group.

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<tr>
<th>Table 1: Types and Examples of Questions in the LifeSpan and Disability Project Questioning Route</th>
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<td><strong>Question type</strong></td>
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Interviewing a focus group, we were with intellectual location of the... Adhering to an it planned the interactions and... opportunity for... building rapport... procedures. Aonex... collection—the included a... person role... repeated during... of... providing this or enhancing the... comfort before sc... Information created the rescuer... potential barriers group ph of... rier was accessible... addressed this... cated and physi... each of the... transportation by groups. Focus group... were completed divided, we... groups by age... to the project. Eight... participants, wee... sites in four towns. Each focus... hours in k... two facilitators us... was developed by the... community po... being used in... Upon arrival... participants were... member who has... during the interv... other participant... of the research to... session. They... followed by opp...
Interviewing process. Before conducting the focus groups, we interviewed the 32 participants with intellectual disabilities individually in a location of their choosing (e.g., home, work). Adhering to an interview guide approach, we planned the interviews to elicit background information and, more importantly, provide an opportunity for the participant and a member of the research team to meet one another (i.e., building rapport) and talk about the project (i.e., explaining the research and the research procedures). Another critical part of this process involved explaining the next step in data collection—the focus groups. This explanation included a description of a focus group and each person's role within one (this information was repeated during the focus groups, see example of introductory question in Table 1 for details). Providing this orientation was a strategy for enhancing the participants' understanding and comfort before actually engaging in the focus group.

Information from the interviews also increased the research team's sensitivity to other potential barriers to involvement in the focus group phase of the project. One potential barrier was accessibility and transportation. We addressed this issue by selecting centrally located and physically accessible locations for each of the focus groups. We also provided transportation by taxi to and from the focus groups.

Focus group process. Once the interviews were completed and the planning issues addressed, we divided the participants into four groups by age (i.e., 12 to 21, 22 to 34, 35 to 59, and 60+ years) to reflect the lifespan nature of the project. Eight focus groups, each involving 4 participants, were organized in accessible public settings in four urban centers and four rural towns. Each focus group was approximately 1.5 hours in length and was moderated by two facilitators using a questioning guide, which was developed by the research team (including the community partners) and piloted before being used in the focus groups.

Upon arriving at the focus group, the participants were greeted by the research team member who had previously met with them during the interview and were introduced to the other participants and to the second member of the research team who would be facilitating the session. These opening introductions were followed by opportunities for socializing over refreshments. The moderators signaled the start of the focus group by inviting the participants to "bring your drinks and snacks and join us at the table." Introductions were repeated and participants were invited to say something about themselves (i.e., the opening question in the questioning route was asked—see Table 1). The facilitator initiated this round of introductions and modeled an example of what was expected.

Launching the formal part of the gathering, the moderator reminded the participants about their interviews in which the purpose of a focus group and each person's role within one had been explained (see Table 1, introductory question). After addressing any participants' questions, we systematically explored the transition, key, summary, and closing questions in the questioning route (see Table 1).

Generally, the moderators directed the focus groups by introducing the questions in the questioning route, modeling active listening skills, and verbally prompting the participants, as necessary, in order to encourage active involvement in the discussion. A notable exception to this moderator-directed approach occurred in a focus group that involved students from the same urban high school. As is chronicled in Vignette 1, one student in this group assumed an active role in facilitating the proceedings:

Jessica, the youngest and shortest member of a focus group of high school students, suddenly spoke. When she did speak, it was with single word expressions or short phrases. An older student in the group (Jessica's opposite) a talkative and outgoing young woman, Shannon clearly had the respect and admiration of her peers. When she told her schoolmates they were off topic, they became quiet. Shannon took over. Perhaps the best example of Shannon's role facilitation was her focus group came about during an exchange that was initiated when the moderator asked, "Who are the people who help you when you need help with things that are difficult for you?" Shannon slowly answered, "the bus driver." Unsure of the meaning of Jessica's remark, the moderator quickly repeated, "the bus driver?" Recognizing the moderator's confusion, Shannon, in great surprise said, "Are you talking about the time you get lost taking the bus?" Smiling shyly, Jessica nodded, "he helped me . . . lost." With Shannon's prompting, Jessica went on to recount the day she got on the wrong bus, how scary this experience was, and how the bus driver helped her get home. When the moderator repeated the story for her confirmation, a beaming Jessica said, "That's it . . . you got it?"
To capture what transpired during the focus group, we audio-recorded each session and later transcribed it (verbatim). Detailed field notes, including nonverbal behavioral responses (e.g., smiling, nodding heads in agreement) also were recorded by one of the moderators during the focus group. Immediately after each session, the moderators discussed and noted, in writing, any additional thoughts and observations (e.g., group dynamics, quality and effectiveness of the moderating strategy). Transcripts of the data were analyzed initially by one of the moderators. This was done using a key theme and constant comparative method until convergent data categories emerged (Merriam, 1988; Strauss & Corbin, 1990; Yin, 1989). A second member of the research team, one who was not involved in the focus groups, subsequently reviewed the transcripts and the emergent themes. This approach, what Denzin (1978) might label investigator or theory triangulation, or alternatively, what Patton (1990) would call triangulation of analysts, was used to enhance confidence in the reliability of our interpretations of the data.

Process for Verifying Interpretations of the Focus Group Data

To further assess the credibility of the researchers' interpretations and to fulfill our ethical obligation to accurately describe the participants' perspectives, we instituted a "review一经 once the focus group data were analyzed (see Figure 1). This involved two meetings—one in an urban setting and one in a rural setting in which the emerging findings were presented to a small group of the original focus group participants. Although all of the focus group participants were invited, not all were able to attend. Nine individuals (5 urban, 4 rural) ranging from age 17 to 72 years participated in these meetings. Paralleling the procedures used in the focus groups, each meeting was actively facilitated by two members of the research team and was structured to encourage discussion but was flexible enough to enable the participants to express their opinions in an unconstrained manner. In explaining the purpose of the meeting, we told the participants:

All of you have been taking part in the same project—yes, we have told you the purpose for the focus group. We have been finished with the project but we still need to do one more important thing—make sure that we've got what you told us during the focus groups right. So that's what we're doing here tonight—talking about some of the things you told us in the focus groups and giving you a chance to add or change anything you think we've missed.

Before discussing the emerging findings, we directly asked participants about their understanding of the meaning of social integration. In the focus groups, this line of questioning was not pursued explicitly. Instead, the focus group questions addressed social integration indirectly by examining the participants' involvement in areas that traditionally have been viewed as indicators of social integration (e.g., having friends, participating in social and leisure activities) (Hutchison & McGill, 1992). To provide a broader context for understanding the emerging findings and as another approach for enhancing the credibility of these findings, we used a prompting hierarchy of questions specific to social integration: 1. What does social integration mean to you? 2. This question can be asked in another way—what does a sense of belonging mean to you? 3. These are big words that mean different things to different people. For some people social integration and a sense of belonging mean____ (an example was offered, e.g., "having friends that you can call to go out and do things with"). What does social integration mean to you?

Although these structured questions were included in the prompting hierarchy, the intention was to use the minimum amount of prompting necessary to facilitate a response from the participants. That is, if the first question produced responses, no further questions would be asked. If after 30 seconds, however, there was no response—a response was not related to the question—the second question would be asked and, if necessary, the third question.

In both meetings, the first question in the prompting hierarchy was sufficient to elicit a response from at least one of the participants and then follow. Once the discussion arrived at a natural conclusion (i.e., people stopped talking), participants who had not responded (verbally or nonverbally) were asked whether they had anything to add. For some participants, this required a restatement of the first question; for others, the second and third questions (and example prompts) were required. This process was followed to ensure that all of the participants (not just those who were most verbal) had an opportunity to contribute to the discussion.

The next step involved presenting the focus group posttest that visual areas (structured—family and home) of brightly coloured cliipped from an image (large x 9 cm). We held the posttest the last time, and a brief each. For example structured recreate, played and the results told us in the focus activities you like school—help you logistics like going going to a movie). Typically, the this description by ing at the picture the types of recrea did the recreation socially integrate received a mixture firmative response more specific insta tance of recreation the participants say the recreation socially integrated. In asking this qual physical gestures a response options (+ ing the tips of the close together, a lo outstretched wided with a side-to-side participants reas their verbal report the researcher, an the universal geo Following this other theme areas.
The next step in the verification meetings involved presenting the results that emerged from the focus group data. This was done through posters that visually depicted each of the theme areas (structured recreation activities, friends, family, and school/work). The posters were made of brightly colored photographs that had been clipped from an assortment of magazines and pasted to large pieces of an odd (102 cm x 92 cm). Before introducing the first poster, we told the participants:

Last week we sat down with you—in the focus groups—you told us a lot about yourselves and what helps you feel socially integrated. Out of everything you told us, four things seemed to be the most important. We just want to look at each of these four areas to make sure we’ve got what you said right and haven’t mixed anything up.

The posters were then presented, one at a time, and a brief description was provided for each. For example, the poster illustrating the structured recreation activities theme was displayed and the researcher said: "From what you told us in the focus groups, it sounded like the activities you like to do for fun—after work or school—help you feel socially integrated. Activities like going for coffee with a friend, or going in a movie."

Typically, the participants elaborated on this description byverbally identifying or pointing at the pictures on the poster that reflected the theme. The recreation activities theme was enjoyed. Once the discussion began, the participants were prompted a second time: "So, do the recreation activities you do help you feel socially integrated?" This question generally received a mixture of verbal and nonverbal affirmative responses. Finally, an effort to gain more specific insights about the relative importance of recreation in promoting social integration, the participants were asked: "Would you say the recreation activities you do help you feel socially integrated a little, a lot, or not at all?" In asking this question, the facilitator used physical gestures as visual cues of the different response options (e.g., a little was signed by placing the tip of the thumb and index finger very close together, a lot was demonstrated with arms outstretched widely, and not at all was illustrated with a side-to-side head shake). Several of the participants responded verbally, others pointed their verbal responses with the gesture used by the researcher, and still others responded with the nonverbal gesture.

Following this process, the posters for the other theme areas (friends, family, school, and work) were subsequently presented and discussed. Interestingly, a measure of the effectiveness of this strategy emerged towards the end of one of the confirmation meetings when several participants spontaneously began offering their views on the relative importance of different theme areas to social integration. Illustrating this unexpected outcome, Vignette 2 illustrates one participant's self-initiated comparison of the influence of school, friends, and family on her experience of social integration:

With the theme posters presented and discussed, the formal part of the meeting is ending. Some of the participants are sitting around the table, while others are enjoying their final cups of coffee and snacks. Still seated at the table is Sarah, a quiet woman who spoke little during the meeting. Making eye contact with one of the researchers, she nods and smiles as the pointer to the poster depicting the "school and work" theme. Getting up and walking towards the poster, Sarah places her finger on a picture of students in a classroom and then slowly turns to gaze at the theme posters for friends. Following her lead, the researcher states "School is a place where you spend time with your friends." Sarah nods her head vigorously and smiles. Pushing further, the researcher asks, "Does being at school with your friends help you feel socially integrated—a sense of belonging?" Mirroring the gesture used by the researcher (indicating a little, versus a lot, or not at all in the meeting), Sarah shakes her head as far as she can stretch and conveys to smile broadly. After a brief pause, Sarah points at the family poster with one hand while formulating the little sign (placing the index finger and thumb together) with the other hand. The researcher responds, "Being school with your friends is a really big part of making you feel like you belong and your family also helps—a little." Appearing encouraged, she leans over and repeats several times, "Sarah, the next few moments repeating each gesture (a little, a little) while pointing at the appropriate posters.

A few days after the meeting, one of the researchers ran into Sarah's father, who observed, in an unobserved comment, that his daughter was "coming out of her shell... growing up, becoming more independent." In fact, on the morning of the verification meeting, Sarah insisted that her father drop her off at the door—he could not come in! In addition, he noted that Sarah was less interested in spending time with her parents than she was in socializing with her classmates.

A record of the verification meetings was achieved by replicating the procedures used in the focus groups (i.e., audiotape, audio-tape transcriptions, detailed field notes). In addition, during the introduction and discussion about the meaning of social integration, one member of the research team textually and visually

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chronicled the verbal and nonverbal responses on a large poster board that was prominently displayed for the participants.

Summary of Key Findings

The methods and strategies described in the present paper produced meaningful and reliable insights about how a small group of individuals with intellectual disabilities, across the lifespan, viewed social integration. To illustrate this point and to provide a broader context for assessing the utility of the procedures used in the Lifespan and Disability Project, we present a summary of the key findings in the following section.

Focusing on the meaning of social integration, we found conflicting results with earlier studies. Specifically, interactions between people with and without disabilities is identified in previous research as one of the defining elements of social integration (Hutchison & McGill, 1992; Birje, 1985; Wolfensberger, 1972). The participants in the present study did not share this perspective. Instead, they viewed social integration as the sense of belonging that emanated from the sharing of time, activities, and experiences with families and friends—indeed, dependent on whether these individuals had a disability or not.

Complementing their understanding of social integration, the participants identified four themes (school/work, structured recreation, friendship, and family) and two subthemes (valued social roles, day program/living situation) that contributed to their perceptions of belonging. These themes acted as neither facilitators or constraints, depending on their presence or absence. That is, when a factor (e.g., school) was present, social integration was promoted and when it was absent, social integration was constrained.

School, work, day program/living situation, structured recreation, and family all served as contexts that fostered perceptions of social integration that were, at times, negative but more often were positive. As can be seen in Table 2, the relative importance of each of these contexts varied with the age of the participants. For the younger individuals, the key settings in which social integration occurred were school, structured recreation programs, and family. Work and structured recreation were of importance for adults, whereas older adults related more on their day placements or living situations as facilitating contexts for social integration. It is also apparent in Table 2 that the importance of family as providers of opportunities for social integration varied with age and, to some extent, with the rural or urban nature of the participants' living environments. In urban settings, families tended to be more actively involved in the lives of their children well into their mid-30s, whereas rural participants typically had less contact with their families by the time they were in their early 20s. In general, the role of family as a context for social integration increasingly declined as the participants got older.

Resistant to the effects of age, valued social roles and friendships emerged as factors that were important across the lifespan. The opportunity to enact valued social roles, particularly those of paid employee and family member, added to some of the participants' feelings of belonging. Although being a friend might also be viewed as a valued social role, the participants did not talk about friendship in this way. Instead, they focused on describing the nature of their friendships. These relationships, in most instances, were confined to the settings in which they were initiated and because of a number of constraints (e.g., lack of transportation), seldom involved interactions across different environments.

Table 2
Summary of Key Findings From the Lifespan and Disability Project

<table>
<thead>
<tr>
<th>Thematic Area</th>
<th>Adolescents (age 12-21)</th>
<th>Young adults (age 22-34)</th>
<th>Adults (age 35-59)</th>
<th>Older adults (age 60+)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Rural</td>
<td>Urban</td>
<td>Rural</td>
<td>Urban</td>
</tr>
<tr>
<td>School</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Work</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Structured recreation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Family</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
<tr>
<td>Day program/living situation</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
<td>✓</td>
</tr>
</tbody>
</table>

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living situation, illy all served as one of social integration but were seen in Table 1. In these con-
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situations. Consequently, although friendships 
he enhanced perceptions of belonging, the con-
tinued previous literature of these relationships 
nced in isolated "islands of social in-
tegration" that varied with each individuals' 
dual activities.

A full accounting of the results of the 
Lifesanp and Disability Project is beyond our 
scope in the present paper. The preceding sum-
mary, however, highlights the key findings and, 
more important, demonstrates the effectiveness 
of the methods and strategies in helping allevi-
ate social integration as it was viewed by the 
project participants with intellectual disabilities.

Discussion and Conclusions

Previous investigators have advocated for 
research that includes the perspectives of indi-
viduals with a disability, particularly when 
studying issues that are highly complex and 
likely to vary according to individual experi-
ences and interpretations (Biklen & Moseley, 
1988; Taylor & Bogdan, 1990). Supporting this 
convention, we based the Lifesanp and Disabili-
ity Project on the belief that social integration,
if it is to be fully understood, must include the 
perspectives of individuals with intellectual dis-
abilities. To operationalize this belief, we ex-
plained a series of strategies recommended in 
previous literature for including these indi-
viduals in the research process. By doing this, 
we created an effective process that included a 
conscious assumption of the credibility of in-
dividuals with intellectual disabilities as re-
search participants, multiple and intensive 
data-collection strategies, and the use of con-
crete data-collection strategies.

Presumption of credibility. From the start of 
the project, we assumed that the participants 
had credible and valuable insights about social 
integration that they would be able and willing 
to share. Although we believed this to be true, 
we did not directly address social integration in 
the questions and discussions during the fo-
cus groups. Instead, the questioning route led 
participants to share their perspectives on is-
ues traditionally thought of as indicators of social 
integration. Progressing through the 
study, the research team questioned the ratio-
nale for this approach and decided to directly 
ask the participants about their views on social 
integration. Discussions during the verification 
meetings clearly indicated that as a group, with 
appropriate prompting and opportunities to 
build on one another's comments, the partici-
pants understood and were able to talk about 
social integration as a concept and how it was 
evoked in their lives.

Starting with a presumption of credibility, 
therefore, is not enough. Researchers must en-
grain ongoing reflection to ensure that par-

cipation is not limited by well-intentioned but 
potentially misguided assumptions about what 
people may or may not comprehend. Further-
more, an assumption of credibility must be re-

dected in data-collection strategies that incor-
porate the supports required to maximize 
meaningful participation (see Concrete Data-
Collection Strategies).

Multiple and intensive data-collection strate-
gies. Consistent with existing literature on 
the importance of multiple data-collection strate-
gies and the use of qualitative research meth-
ods in studying socially constructed issues, we 
employed interviews, using an interview guide 
approach, and focus groups. The standardized 
interview technique (i.e., rigid adherence to 
a fixed set of carefully worded questions that 
are asked in a precise sequence) has been the pre-
ferred mode of interviewing individuals with 
intellectual disabilities in previous research; 
focus groups, as they were articulated in the 
pretest study, have not been used frequently 
(Malik et al., 1991; Sigelman et al., 1983). 
Consequently, although qualitative methods 
have been used in previous research that in-
volves participants with intellectual disabilities, 
the Lifesanp and Disability Project offered a 
unique illustration for effectively combining 
interview guide interviews, focus groups, and 
verification meetings within a single study.

Implementing this three-pronged strategy 
enabled several meetings with the research par-
ticipants over the 2-year project. These con-
tacts provided multiple and rich sources of 
information that enabled triangulation and mem-
 ber checks, which enhanced confidence in the 
credibility of the data analysts and results.

Beyond generating rich data, multiple con-
tacts with the participants facilitated the build-
ing of rapport. These contacts provided multiple 
opportunities for the participants to meet mem-
bers of the research team and one another. In 
addition to meeting, each contact included a 
number of other tactics directly aimed at fos-
tering rapport (e.g., interview guide approach 
to create a relaxed and conversational setting 
for the individual interviews; transportation to
and from the focus groups; opportunities for socializing; use of well-known and valued community settings for the focus groups and verification meeting. Evidence of the effectiveness of these efforts was apparent in spontaneous social interactions and group jokes that were shared during the focus groups and the verification meeting as well as the nature of the findings that were derived.

Although the need for multiple data-collection approaches was addressed, the extent to which the project utilized "intensive" strategies is subject to debate. In particular, those subscribing to other qualitative research traditions that rely on participant observation as a central data-collection strategy (e.g., ethnography) would charge that relatively little time was spent with the participants. Others might contend that interactions over a 2-year period is incentive, at least when compared to other strategies that involve single points of contact. Independent of one's position in this debate, what was done in the project supports the well-established methodological udage that repeated contact in a variety of data-collection settings allows richer data to be collected and a better understanding of the participants' points of view.

Concrete data-collection strategies. In previous literature, investigators have contended that concrete data-collection strategies are essential in research that involves individuals with intellectual disabilities. Our experiences in conducting this project support this contention and provide numerous examples of effective strategies for making data-collection procedures concrete. For example, the individual interviews were conducted using an interview guide approach, which provided structure while creating a relaxed and conversational setting. The interviews also included a description of the upcoming focus groups in order to assure that the participants would arrive at these sessions having some understanding of the process and their roles. This description was reviewed as the start of each focus group.

During the focus groups, care was taken to introduce people to one another, and the moderators actively facilitated each session (e.g., through verbal prompting, modeling active listening, and discussion skills) to promote discussion. A questioning matrix was used to provide a flexible structure for accommodating a variety of different types of questions (e.g., "interviewer key, summary") and follow-up prompts. In addition, the focus groups were smaller than is usually recommended (i.e., 4 participants vs. 6 to 10) to ensure that the participants had sufficient time, opportunity, and support to discuss their perspectives (Knagge, 1994). The verification meeting included an abstract to concrete question hierarchy to explore the participants' understanding of social integration, and visual and gestural cues were used to assist in assessing the accuracy of the researchers' interpretations of the focus group data.

In conclusion, operating on a presumption of the credibility of individuals with intellectual disabilities as central figures in the research process, we incorporated individual interviews, focus groups, and verification meetings in a qualitative study of social integration. As illustrated in this paper, these approaches, when coupled with efforts to establish rapport, instruction, and concrete data-collection strategies, were effective in facilitating the meaningful participation of these individuals. One of one or more of these examples in subsequent research, therefore, could prove effective in extending our understanding of the experiences of individuals with intellectual disabilities.

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Authors: JENNIFER B. MACTAVISH, PhD, Asst. Professor and Graduate Program Coordinator; MICHAEL J. MAHON, PhD, Associate Dean, Research and Graduate Programs, Faculty of Physical Education and Recreation Studies, and Director of the Health, Leisure and Human Performance Research Institute, 313 Max Bell Centre; ZANIA MARIE LUTFIYYA, PhD, Associate Professor, Faculty of Education, University of Manitoba, Winnipeg, Manitoba, Canada, R3T 2N2.

Follow-up prompts were smaller than 4 participants vs.

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