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

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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 cueing 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 (Goode, 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, Hoge, & 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 presuming 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 or event are inherently valuable and equally useful (Ferguson, Ferguson, & Taylor, 1992; Taylor, Bogdan, & Lutfiyya, 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

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of view (Bogdan & Biklen, 1992; Taylor & Bogdan, 1998). Such a position has both theoretical and practical implications for conducting research. It places an obligation on researchers to actively seek out, document, and analyze the "lived-in" experiences of individuals who may have been seen in other contexts as not having very much to offer (Taylor & Bogdan, 1994). It also means that researchers must be prepared to modify data-collection procedures, when necessary, to enable participation (Biklen & Moseley, 1988). The willingness of researchers to incorporate necessary adaptations and supports, however, is contingent on the presumption that perspectives of people with intellectual disabilities are credible and valuable.

Multiple and intensive data-collection strategies. Qualitative research methods (e.g., case studies, participant observation) are particularly well-suited for translating a presumption of credibility into the collection of meaningful data from individuals with intellectual disabilities (Bercovici, 1983; Bogdan & Biklen, 1992; Taylor & Bogdan, 1998). This position stems from the assertion that qualitative methods, when appropriately used, are conducive to building and maintaining rapport between the researcher and informant (Biklen & Moseley, 1988; Taylor, Bogdan, & Lutfiyya, 1995). In some cases, rapport is achieved through multiple contacts with the participants over prolonged periods of time (Taylor & Bogdan, 1998). In other cases, deliberate and conscious efforts to establish rapport are built into less intensive data-collection strategies, for example, within a single interview (Malik, Ashton-Schaeffer, & Kleiber, 1991). Independent of the approach used, most researchers have identified rapport as critical to the development of trust and comfort between the participant and the researcher, which enhances the quality and trustworthiness of the data (Biklen & Moseley, 1988; Malik, Ashton-Shaeffer, & Kleiber, 1991; Taylor et al., 1995; Taylor & Bogdan, 1998).

Among the qualitative data-collection strategies that have been recommended, long-term participant observation is recognized as ideal for getting to know a person and developing an appreciation and understanding of his or her world view (Biklen & Moseley, 1988). Qualitative interviews and focus groups also are acknowledged as beneficial, albeit less frequently used, approaches for collecting the perspectives of individuals with intellectual disabilities (Malik, Ashton-Shaeffer, & Kleiber, 1991; Sigelman et al., 1983; Wyngaarden, 1981).

Concrete data-collection strategies. Beyond advocating use of qualitative research methods for collecting data and building rapport, investigators have clearly expressed the need for concrete strategies that enable the participation of individuals with intellectual disabilities (Dattilo, Hoge, & Malley, 1996; Malik, Ashton-Shaeffer, & Kleiber, 1991; Sigelman et al., 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 confusing than clarifying" (p. 158) when employed with individuals who do not use a lot of language in their communication. Consequently, a number of researchers have offered advice for ensuring that data-collection strategies are concrete enough to stimulate comprehension and responsiveness.

Dattilo et al. (1996) described a series of guidelines to enhance the validity and reliability of responses provided by adults with intellectual disabilities on a standardized interview instrument. These guidelines include (a) having a broad range of items that focus on the issue/question of interest, (b) avoiding temporal concepts in the questions, (c) providing concrete visual cues for some of the questions, (d) alternating the sequence of responses (in order to reduce response bias), (e) using different types of questions (in order to identify potential acquiescence), (f) having experts evaluate the interview questions for clarity and appropriateness, and (g) piloting the instrument.

Malik, Ashton-Schaeffer, and Kleiber (1991) have offered support for these guidelines and suggested that questions with multiple choice and dichotomous (e.g., yes/no) response formats may be less reliable than are open-ended questions. They emphasized the need for a variety of question formats, particularly open-ended questions that can be asked in different ways at different times during the interview. Offering a slightly different perspective on this issue, Sigelman et al. (1983) suggested that verbatim repetition of selected interview questions, followed, if necessary, by preplanned rephrasings of the selected questions was most effective in enhancing comprehension and responsiveness. Furthermore, Biklen and Moseley (1988) pro-

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 concepts (e.g., social integration, quality of life) that are subject to multiple interpretations (Biklen & Moseley, 1988; Goode, 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 = 38.94, standard deviation [SD] = 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, equally, 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 "retired," 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 retirement transition

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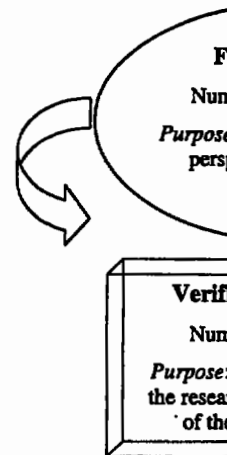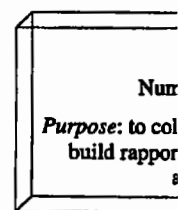ure 1). In the follo
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Strategies and Processes for Involving Participants With Intellectual Disabilities

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.
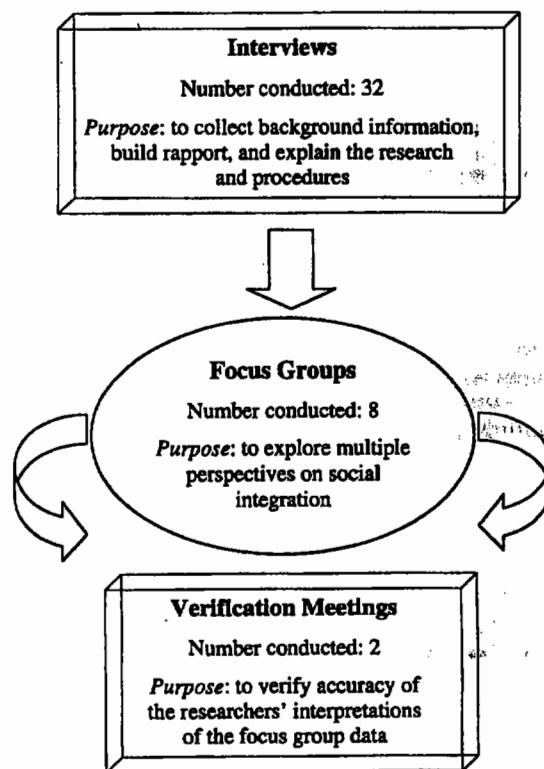

Figure 1. Overview of data-collection strategies, implementation of strategies, and verification of interpretations.

Data-Collection Strategies: Description and Rationale

Our primary data-collection strategies were qualitative interviews and focus groups. Three basic types of qualitative interviews are de-

scribed in the literature: (a) the informal conversational interview, (b) the standardized open-ended interview, and (c) the interview guide approach (Merriam, 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., 1991; Sigelman et al., 1983). This approach affords little flexibility and is most often used when multiple interviewers are involved in data-collection (Merriam, 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 route (Krueger, 1998). A *topic guide* is simply a list of words or phrases that reminds the researcher of key issues to be explored dur-

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 entirely 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 and focus groups were instituted in a sequential, two-step data-collection process (see Figure 1): interviewing and focus group.

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Table 1
Types and Examples of Questions in the Lifespan and Disability Project Questioning Route

Question type	Example of the question asked and sample probes
Opening	Not all of us have met before, so what would you like to tell everyone about yourself? Sample follow-up probes: How old are you? Where do you live?
Introductory	Remember when we got together before, I told you about focus groups. That's why we are here tonight—for the focus group. At a focus group, questions are asked and everybody talks about their answers. People can answer whatever way they like because these questions don't have right or wrong answers. Remember, everyone can't talk at once, so when someone else is talking just wait until they are done and then you can add to what they've said or talk about something different. Does anyone have any questions about what we are going to do?
Transition	What can you tell us about your friends? Sample follow-up probes: How did you meet___ [your friend]? What kinds of things do you do with your friends?
Key	Based on what you've told us about your friends, do you think friends are important? Sample follow up probes: How come? How does having friends make you feel?
Summary	From everything you've said tonight, it sounds like most of you like school because you get to be with your friends and that helps you feel like you belong. Is that true?
Closing	We've talked a lot about the different kinds of things you are involved in with your friends and your family. Is there anything else you'd like to tell us about any of these things before we go?

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 to 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 pilot tested 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 shyest member of a focus group of high school students, seldom spoke. When she did speak, it was with single word expressions or short phrases. Shannon, an older classmate, was 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, prodded them to share personal stories that were relevant to the discussion, and reminded participants to "let other people talk"—they responded positively. In essence, once the moderator introduced the question, Shannon took over. Perhaps the best example of Shannon's role in facilitating the 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?" Jessica slowly answered, "the bus driver." Unsure of the meaning of Jessica's remark, the moderator quizzically repeated, "the bus driver?" Recognizing the moderator's confusion, Shannon, interjected: "Are you talking about the time you got 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 groups, we audiotaped 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 credibility 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 "member checking" process 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—remember when we got together for a focus group. We're almost 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 three 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—or 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 others then followed. 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.

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The next step in the verification meetings involved presenting the results that emerged from the focus group data. This was done using 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 cardboard (102 cm x 92 cm). Before introducing the first poster, we told the participants:

Last time 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 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 missed anything.

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 to a movie."

Typically, the participants elaborated on this description by verbally identifying or pointing at the pictures on the poster that reflected the types of recreation activities they most enjoyed. Once the discussion began to ebb, 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, in 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 tips 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 paired 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 final cups of coffee and snacks. Still seated at the table is Sarah, a quiet woman who said little during the meeting. Making eye contact with one of the researchers she nods and smiles as she points 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 poster 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. Probing 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 swings her arms out as far as she can stretch and continues to smile broadly. After a brief pause, Sarah points at the family poster with one hand while forming the a little sign (placing the index finger and thumb together) with the other. The researcher responds by saying, "Being at school with your friends is a really big part of making you feel like you belong and your family also helps—a little." Apparently excited that the researcher understands her point, Sarah spends the next few moments repeating each gesture (a lot, 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 unsolicited comment, that his daughter was "coming out of her shell . . . growing up, becoming more independent." In fact, on the evening 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 introductions and discussion about the meaning of social integration, one member of the research team textually and visually

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; Nirje, 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—independent of 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 either 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 relied 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 families as providers of opportunities for social integration varied with age and, to some extent, with the rural or urban nature of the participants' living environment. 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/or 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

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

Theme	Adolescents (age 12–21)		Young adults (age 22–34)		Adults (age 35–59)		Older adults (age 60+)	
	Rural	Urban	Rural	Urban	Rural	Urban	Rural	Urban
School	√	√						
Work			√	√	√	√		
Structured recreation	√	√	√	√	√	√		
Family	√	√		√				
Day program/ living situation							√	√

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situations. Consequently, although friendships enhanced perceptions of belonging, the context-dependent nature of these relationships often resulted in isolated "islands of social integration" that varied with each individuals' daily activities.

A full accounting of the results of the Lifespan and Disability Project is beyond our scope in the present paper. The preceding summary, however, highlights the key findings and, more important, demonstrates the effectiveness of the methods and strategies in helping us learn about 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 individuals with a disability, particularly when studying issues that are highly complex and likely to vary according to individual experiences and interpretations (Biklen & Moseley, 1988; Taylor & Bogdan, 1990). Supporting this contention, we based the Lifespan and Disability Project on the belief that social integration, if it is to be fully understood, must include the perspectives of individuals with intellectual disabilities. To operationalize this belief, we expanded on a series of strategies recommended in previous literature for including these individuals in the research process. By doing this, we created an effective process that included a conscious presumption of the credibility of individuals with intellectual disabilities as research participants, multiple and intensive data-collection strategies, and the use of concrete 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 focus groups. Instead, the questioning route led participants to share their perspectives on issues traditionally thought of as indicators of social integration. Progressing through the study, the research team questioned the rationale 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 participants understood and were able to talk about social integration as a concept and how it was enacted in their lives.

Starting with a presumption of credibility, therefore, is not enough. Researchers must engage in ongoing reflection to ensure that participation is not limited by well-intentioned but potentially misguided assumptions about what people may or may not comprehend. Furthermore, an assumption of credibility must be reflected in data-collection strategies that incorporate the supports required to maximize meaningful participation (see *Concrete Data-Collection Strategies*).

Multiple and intensive data-collection strategies. Consistent with existing literature on the importance of multiple data-collection strategies and the use of qualitative research methods 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 preferred mode of interviewing individuals with intellectual disabilities in previous research; focus groups, as they were instituted in the present 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 involves participants with intellectual disabilities, the Lifespan 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 participants over the 2-year project. These contacts provided multiple and rich sources of information that enabled triangulation and member checks, which enhanced confidence in the credibility of the data analyses and results.

Beyond generating rich data, multiple contacts with the participants facilitated the building of rapport. These contacts provided multiple opportunities for the participants to meet members of the research team and one another. In addition to meeting, each contact included a number of other tactics directly aimed at fostering 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 meetings). 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 meetings 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 intensive, 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 adage 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 at 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 route was used to provide a flexible structure for accommodating a variety of different types of questions (e.g., intro-

ductory, 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 (Krueger, 1994). The verification meetings 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. Use of one or more of these examples in subsequent research, therefore, could prove effective in extending our understanding of complex, socially constructed notions to include the perspectives of persons with intellectual disabilities.

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