INCLUSIVE EVALUATION: CONDUCTING PROGRAM EVALUATIONS WITH INDIVIDUALS WITH COGNITIVE DISABILITIES

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Dedication

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Abstract

Individuals with cognitive disabilities (IWCD), such as developmental disabilities, traumatic brain injuries and dementia, make up over 4% of our population in the United States. This number is expected to grow as our population ages, particularly in the cases of disability caused by dementia and stroke. IWCD have been historically marginalized through the suppression of their voices and a lack of power over their own lives. While the advocacy movement has helped IWCD achieve self-empowerment and abolish the inhumane research practices of the past, the inclusion of IWCD in program evaluations has been limited. Exclusion from evaluation means that IWCD have less influence over the programs and services on which they rely. This study examined the extent to which and in what ways IWCD have been included in evaluations, the common obstacles to inclusion, and why evaluators do or do not include IWCD in their evaluations. Using a mixed-method approach, the researcher conducted over 500 surveys and 12 interviews with evaluators, primarily with members of the American Evaluation Association, who have a wide range of experience working with IWCD. The results show that evaluators believe including IWCD in evaluations is an ethical necessity, but many evaluators do not know how to identify or accommodate IWCD. Many evaluators have not considered including IWCD in their evaluations as participants or on their evaluation teams. Additionally, concern over resources, ethical review, and validity limit inclusive practice. Evaluators who have conducted evaluation projects with IWCD have faced these challenges and offer solutions and reassurances. The dissertation concludes with several recommendations for increasing inclusion in the evaluation field.

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Chapter 1: Problem Statement

Introduction

In the mid-1950s, the Willowbrook State School on Staten Island, New York housed over 6,000 children and adults with severe intellectual disabilities (Feudtner & Brosco, 2011; Krugman, 1986). The institution was overcrowded and understaffed, and deplorable conditions led to the rampant spread of diseases, including hepatitis. Doctors Saul Krugman and Robert Ward were hired as infectious disease consultants to help contain the spread of disease through their research on potential treatments and a vaccine. The doctors conducted what became known as the Willowbrook Hepatitis Studies, in which they injected new resident children with hepatitis in order to observe its progression and response to different treatments. The researchers argued that these children would have contracted the disease anyway if they stayed in the institution and that as subjects they would receive better medical care than other residents (Krugman, 1986). Twenty years into the study, public outrage finally led to the termination of the research, and critics accused the researchers of taking advantage of the vulnerable children and of manipulating and deceiving the consenting parents (Feudtner & Brosco, 2011; Iacono & Carling-Jenkins, 2012; Layman, 2009). The Willowbrook Hepatitis Studies have become a notorious example of the unethical and inhumane research conducted on vulnerable individuals with intellectual disabilities for the benefit of others.

Statement of the Problem

Individuals with cognitive disabilities (IWCD) make up approximately 4.3% percent of the United States’ population (US Census Bureau, 2008). This group includes individuals with intellectual disabilities (ID, e.g., Down syndrome and autism, approximately 22%), brain injury (approximately 27%), chronic severe mental illnesses (e.g., Schizophrenia, approximately 27%) neurodegenerative diseases (e.g., Alzheimer’s disease, approximately 20%), and disability from stroke (e.g., aphasia, approximately 4%; Braddock, Rizzolo, Thompson, & Bell, 2004). The rates of certain cognitive disabilities are expected to grow significantly as the US population ages and medical advances prolong lives. Projections suggest the worldwide prevalence of dementia, which currently affects approximately 24 million, will quadruple by 2050 (Prince et al., 2013; Reitz & Mayeux, 2014). Alzheimer’s disease, the most common cause of dementia, will increase by 100% by 2040 in the developed world (Ferri et al., 2006; Reitz & Mayeux, 2014). Cognitive disabilities may range from mild to severe and may include a variety of symptoms such as difficulty with memory, problem solving, decision making, language comprehension and expression, and below normal intelligence as diagnosed by intelligence tests (Braddock et al., 2004; Parmenter; 2001; US Census Bureau, 2008).

Historically, individuals with cognitive disabilities have been marginalized from society and prevented from having control over their own lives (Freedman, 2001; Mertens, 2001; Molinari, Gill, Taylor, & Charles, 2011). The United States institutionalized IWCD in asylums for the insane and mentally retarded through the 1970s (Harbour & Maulik, 2010; Parmenter, 2001), effectively isolating them from society and barring their participation in community programs. These individuals had no say in the functioning of the institutions, and programmatic changes were made by outside “experts” and policy makers.

The evaluation and research studies in which IWCD were included as subjects were often mandatory, with no informed consent from the participants or their guardians.

Two prominent examples of such research that occurred into the 1970s are the previously mentioned Willowbrook Hepatitis Studies and the radiation experiments (Buchanan, 1996; Krugman, 1986; Layman, 2009). During the radiation experiments, researchers from the Quaker Oats Company fed small amounts of radiation to residents at two institutions for individuals with ID to study the effect on mineral absorption (Buchanan 1996). In both of these examples, the residents' guardians were misled about risks of the research, and the subjects were unable to provide informed consent for themselves. In response to such unethical studies, the federal government implemented regulations for federally funded research, requiring review by Institutional Review Boards (IRBs). Although these regulations were designed to protect the most vulnerable populations, such as children and prisoners, many evaluation projects do not require any review by IRBs. Evaluations often do not provide results that can be generalized beyond the programs of focus and are thus not considered research (AEA, 2005). If the evaluation funder does not require human subjects review and the project is not considered research, the evaluator is not mandated to seek IRB approval. Today, few guidelines exist for evaluators who desire to include IWCD in their studies. The published ethical guidelines for evaluators and evaluations do not provide specific standards for including IWCD (AEA, 2004; Yarbrough, Shulha, Hopson, & Caruthers, 2011).

Since the 1970s, family advocacy efforts have revealed the inhumane treatment of the residents of such institutions to the public, and community-based treatments were developed, leading to deinstitutionalization (Harbour & Maulik, 2010; Parmenter, 2001). Numerous federal and local social programs, nonprofits, and religious organizations have evolved to serve IWCD. These programs strive to reduce homelessness, provide independent living and job-training assistance, and run group homes, assisted living centers, and day programs for individuals who are not employed. In addition to programs specifically targeting IWCD, many IWCD go to schools, libraries, gyms, etc. and are otherwise fully engaged in society. The Americans with Disabilities Act of 1990 (ADA, 1990, 2008) supports the inclusion of individuals with disabilities in all parts of society and prevents discrimination based on ability. Furthermore, advocates have fought for IWCD to have control over their lives and influence on the programs in which they participate, including programmatic changes (Molinari et al., 2011).

For IWCD to have the ability to influence and improve the programs on which they rely, they need to be included as participants in the evaluations of those programs and as members of evaluation teams themselves (Molinari et al., 2011). Such inclusion of IWCD in research and evaluation can require additional time and resources for the development of appropriate accommodations (Mertens, 2001). Diversity in culture and severity of impairment among IWCD further complicate attempts to create inclusive designs. Evaluators are also faced with more complex ethical challenges when evaluating programs that include IWCD, such as whether an individual can provide informed consent or should be represented by a proxy. Yet excluding IWCD from evaluations may continue their marginalization and dependence on others.

The field of evaluation has recognized the benefits of including program participants in the evaluation process (Chouinard & Cousins, 2009; Yarbrough et al., 2011). The purpose of program evaluation is to determine the quality, worth, or merit of a program to aid clients in their decisions about program development, expansion, or termination (Fitzpatrick, Sanders, & Worthen, 2004). Because program evaluation results can have a significant impact on policies and services, it is essential that evaluators have a full understanding of the program under consideration. Including IWCD in the evaluation process helps increase representation of stakeholders and limits bias. Involvement from all stakeholder groups also ensures that these individuals have influence in the evaluation process and results. When individuals with disabilities and their families are not included in evaluations, their needs and experiences are ignored, and those groups may become further marginalized by society (Mertens, 2001). Therefore, including individuals with disabilities in evaluations is integral to an evaluation's validity and also serves a larger social purpose. Unfortunately, there has been little discussion in the evaluation literature about if and how IWCD are being included in evaluations.

Research Questions

This study addresses the inclusion of IWCD in program evaluations by examining the extent to which IWCD have been included in evaluations, how evaluators have accommodated IWCD, and how evaluators perceive issues around including IWCD. The research focuses on IWCD versus all disabilities because individuals with physical disabilities alone would not have limited cognitive abilities and would therefore have very different challenges in participating. The study used a sequential explanatory mixed methods design because it allows for an understanding of the extent of different practices through quantitative methods, and those findings can then be used to identify areas to explore in depth via qualitative methods (Creswell & Plano-Clark, 2010). The specific questions studied were as follows:

Question 1: What is the nature and degree of the participation of individuals with cognitive disabilities in program evaluation?

Question 2: To what extent do evaluators consider individuals with cognitive disabilities when planning evaluations?

Question 3: Why do evaluators choose to include or not include individuals with cognitive disabilities in the evaluation process?

The first question is descriptive and focuses on the level and type of inclusion in current evaluation practice. The second question examines if evaluators are cognizant of the presence of IWCD in programs and if they think about the need for accommodations or inclusion. The third question explores the decision processes of evaluators who are evaluating programs with IWCD when they are deciding whether or not to provide accommodations or inclusive approaches. Overall, the answers to these questions provide information about current evaluation practices and evaluator awareness of IWCD.

Statement of Significance

The evaluation field has recognized that individuals with disabilities have been historically excluded from having a voice in the development of programs and policies that directly impact their lives (Jacobson, Azzam, & Baez, 2013; Mertens, 1995; 2001). Yet little research has examined the extent to which IWCD have been included in evaluations as participants or as members of the evaluation team, how they can be included, or what barriers prevent evaluators from including IWCD. The limited attention to IWCD in the evaluation literature may reflect routine clinical practice. Including IWCD raises important ethical concerns about informed consent, interpretation of data, and the use of proxies, of which evaluators must be informed to better guide practice. In order for IWCD to have ownership in essential policies and programs, evaluators need to be aware of IWCD and knowledgeable about accommodations to facilitate their involvement.

Recently, Jacobson et al. (2013) conducted a review of the evaluation literature to examine the degree and type of participation that IWCD have had in evaluations. The study provides an overview of inclusion in articles published in select evaluation journals, but does not address the reasons behind the decisions to include or exclude IWCD. Their study is limited because most evaluations are not published in evaluation journals, and the small number of studies they examined may not be representative of evaluation practice. This dissertation expands on previous research by examining in depth the extent and ways that IWCD participate in routine evaluations. It also explore the reasons behind these decisions. This research examines the knowledge base of the evaluation field by applying the accommodation and ethical decisions made in research studies to program evaluations. When disseminated, the results may help encourage the evaluation field to be more inclusive and provide guidelines to achieve that goal.

Definitions of Key Terms

Several key terms that often have multiple definitions will be used throughout this document. The definitions that will be used in this thesis are provided here:

Cognitive disabilities – Disabilities, including intellectual disabilities, that include a limitation of an individual's ability to think, often presented through difficulties with remembering, conceptualizing, concentrating, making decisions, planning, organizing, and self-expression (Braddock et al., 2004; US Census Bureau, 2008).

Disability – “A physical or mental impairment that substantially limits one or more major life activities” of an individual (ADA, 1990).

Inclusion – The act of involving individuals with disabilities in an activity as fully as possible while making necessarily accommodations to support their participation.

Inclusive evaluation – An evaluation approach that strives to include IWD as fully as possible throughout the evaluation process.

Intellectual disabilities (ID) – “Characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills. This disability originates before the age of 18” (American Association of Intellectual and Developmental Disability, 2013). Intellectual disability includes developmental disability, formally known as mental retardation.

Program evaluation – The process of determining the quality, worth or merit of a program to aid clients in their decisions about program development, expansion or termination (Fitzpatrick et al., 2004).

Universal design – “The design of products and environments to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design” (Connell et al., 1997).

Chapter 2: Literature Review

Introduction

The inclusion of IWCD in evaluations has received little attention in the evaluation field, although recently scholars have addressed the importance of inclusive practice through an emphasis on cultural competence (CC). Recognizing that individuals with disabilities (IWD) represent multiple, diverse cultures, disability has been included in the discussion on cultural competence (American Evaluation Association [AEA], 2011; Yarbrough et al., 2011). Many evaluators now view CC as essential to quality evaluations and as an important skill for evaluators (AEA, 2011; Botcheva, Shih, & Huffman, 2009; Chouinard & Cousins, 2009; Madison, 2007; Morris, 2011; SenGupta, Hopson, Thompson-Robinson, 2004; Smith et al., 2011; Stevahn, King, Ghere, & Minnema, 2005; Yarbrough et al., 2011). Much of the specificity in the cultural competence literature is on ethnic and geographical differences rather than disability. Little has been written on how to include individuals with disabilities, particularly cognitive disabilities, in evaluations. Some guidelines exist on how to be culturally competent and inclusive, but those guidelines are intentionally broad and provide little information on the specific factors that are important when working with the disability community (AEA, 2011).

There is a larger body of literature on including IWCD in research. The primary difference between research and evaluation is that the purpose of research is to contribute to the general knowledge, whereas the purpose of evaluation is to make decisions about a program (Russ-Eft & Preskill, 2009). Researchers choose to conduct studies in a specific context when they believe the methods will provide valid answers to their questions.

Evaluators conduct studies even when the methods options are not ideal, and those evaluations can have immediate impacts on the participants through programmatic changes (Fitzpatrick, et al., 2004). Since researchers and evaluators use the same methods in their studies, much of the research literature is applicable to the evaluation field. The ethical and methodological challenges that have been discussed in the research literature, such as issues around recruitment, consent, and accommodations are likely faced by evaluators as well, since evaluators primarily follow a process similar to that of research and are also morally and ethically responsible for their studies. In addition, many studies presented in the research literature could be defined as program evaluations (AEA, 2005). Because of evaluation's primarily local focus, the need for attention to these issues may be less clear to the evaluators or program staff.

IWCD have been involved in research and evaluation in many different levels, from acting as participants to running the study (Jacobson et al., 2013). The majority of studies have included IWCD as participants, so much of this review focuses on issues around participation. In addition, IWCD have become increasingly involved in the research process beyond the role of the subject, and those approaches to inquiry are also reviewed. To ensure that this review reflects current topics on inclusion of IWCD in research and evaluation, most of the studies included have been published within the last 10 years and within the last 5 years for more heavily researched topics such as consent and use of proxies.

Recent research and evaluation studies that have involved individuals with cognitive disabilities are situated in a historical context of researcher abuse to vulnerable human subjects and ethics committees' attempts to protect subjects in response to those abuses. The literature reviewed in this chapter demonstrates how researchers and evaluators have included individuals with cognitive disabilities (IWCD) in their studies, explores the challenges they have encountered, and the strategies they have developed in response to those obstacles.

This dissertation focuses on individuals with a range of cognitive disabilities, so studies are included that were conducted with individuals with many different disabilities, including intellectual disability (ID), dementia, traumatic brain injury (TBI), aphasia, and schizophrenia. Initial search terms, which were used in various combinations, included "inclusion," "inclusive methods," "research methods," "accessible," "participatory," "emancipatory," "cognitive disability," "intellectual disability," "traumatic brain injury," "dementia," "schizophrenia," "aphasia," "proxy", and "consent." These searchers revealed the majority of literature, and reviews of the reference list for each article led to additional sources. Much of the literature comes from Western Europe, particularly the United Kingdom, and Australia, as journals from those countries appear to publish more on the issue of inclusion in research and evaluation.

Inclusion of IWCD as Participants

Including IWCD as participants in research or evaluation presents unique challenges for investigators from the recruitment and consent process through data analysis and reporting. This section explores the ethical issues around including IWCD as participants, as well as methodological obstacles and solutions.

The Ethics of Inclusion

There have been many reports of how research participation, consensual or not, has harmed IWCD. These cases include the biomedical research conducted during World

War II that was reviewed during the Nuremberg trials and cases made public by advocates of IWCD such as the Willowbrook Hepatitis Studies and the Human Radiation Experiments (Freedman, 2001; Morton & Cunningham-Williams, 2009). Ethics committees around the world have based their standards of ethical research practice on the reports written in response to these atrocities, including the Nuremberg Code, the Belmont Report, and the Declaration of Helsinki (National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978; Shuster, 1997; World Medical Association, 2004). Even today researchers note that participation can produce negative experiences for IWCD. For example, Hubbard, Downs, and Tester (2003) found that for patients with dementia, being reminded of their inability to recall details about their lives, such as if they were married, can be distressing. Participants can become embarrassed about their disability or behavior.

Many research and evaluation projects are required to meet federal regulations of the Protection of Human Subjects (Code of Federal Regulations 45, Part 46, 2009) through the approval of an institutional review board (IRB; AEA, 2005). In cases where IRB approval is not required, ethical practices require investigators to follow similar practices, particularly around informed consent (Appelbaum, 2010). The ethics standards for program evaluations require evaluators to consult human subject committees' requirements in their practice (Yarbrough et al., 2011).

The US Code of Federal Regulations 45, Part 46, lists mentally disabled persons as a vulnerable population, but fails to provide additional protections for these individuals as it does for the other specified vulnerable populations of children, pregnant women, and prisoners (Black, Rabins, Sugarman, & Karlawish, 2010; Freedman, 2001; Sherratt, Soteriou, & Evans, 2007; Swaine, Parish, Luken, & Atkins, 2011). Researchers note that standard practice for children is not suitable for adults who are unable to consent, since adults, particularly those with dementia or brain injury, may have at one point been able to consent (Freedman, 2001; Yarborough, 2002). In addition, unlike children, all adults with cognitive disabilities have a lifetime of experiences and values on which to base their decisions (Black et al., 2010; Yarborough, 2002). Feudtner and Brosco (2011) argue that IWCD, specifically with ID, do not require special protections by IRBs because the protections are standard for all human subjects, including those with cognitive disabilities. In a study on 199 IRB members' and researchers' perceptions of studies with people with ID, the researchers found that those participants viewed individuals with ID as particularly vulnerable and in need of special protection (McDonald et al., 2009).

Researchers and advocates for IWCD have called for an increase in the participation of IWCD, providing these individuals the right to participate and benefit from that participation as subjects and as members of the research teams (Cheston, Bender, Byatt, 2000; Graor & Knapik, 2013; McDonald & Kidney, 2012; McDonald, 2012; Northway, Howarth, & Evans, 2015). These authors note that IWCD have been greatly excluded from society, specifically as participants in research projects. Particularly in the case of dementia, a combination of age, cognitive deficits, and the fact that individuals with dementia often live in institutions means they are frequently excluded from having their voices heard about the services on which they increasingly rely (Cheston et al., 2000). Whenever possible, individuals with disabilities should represent themselves in evaluations because they know their experiences best (Gill, 1999; McDonald, 2012).

Many researchers have mentioned that IWCD appreciate having the opportunity to participate in a research study and share their views and experiences (Boothroyd, 2000; Graor & Knapik, 2013; McAllister, Kelly, Manning, & Holland, 2013; Taylor et al., 2010). Even in an invasive clinical trial, McAllister et al. (2013) reported that participants enjoyed the research process, including travelling to the research site and meeting others with similar experiences, providing an opportunity for new social relationships. Participants felt that it was important that they have the opportunity to participate in research that could benefit both them and society as an altruistic act. Boothroyd studied the impact of participation in a year-long program for adults with mental illness. Based on interview and questionnaire results from over 523 participants, Boothroyd found that 96% of the participants had a positive experience with the research, although 9% felt anxious during the process and 17% felt the questions were invasive.

Similarly, Taylor et al. conducted a study with individuals who have schizophrenia and found that the majority had a positive experience and found participation enjoyable and altruistic. Some participants, however, found certain questions and tasks distressing. McDonald, Kidney, and Patka (2013) used interviews and focus groups to examine the experiences of 16 individuals with ID. The individuals wanted to participate in research studies to both potentially improve their own lives and to help others with ID. Participation also provided the individuals new experiences and chances to meet new people, helping with frequent social isolation. Researchers and reviewers emphasize that individuals have the right to put themselves at risk and to weigh the risks and benefits when consenting to a study (Lai, Elliott, & Ouellette-Kuntz, 2006; McAllister et al., 2013; McDonald, 2012).

Some researchers believe that the standard regulations for IRBs have become overly restrictive without allowing for alternative processes, resulting in reduced participation of IWCD (Iacono & Carling-Jenkins, 2012; Iacono, 2006). Researchers argue that these practices are discriminatory and that IRBs must not assume IWCD cannot participate in research, even if different consent procedures are required (Alzheimer's Association, 2004; Hellstrom, Nolan, Nordenfelt, & Lundh, 2007; Slaughter, Cole, Jennings, & Reimer, 2007). For example, Slaughter et al. (2007) state, "Assuming people with dementia are unable to participate in research reinforces negative stereotypes of incapacity, and denies them the opportunity to make a meaningful contribution to research" (p. 27). While IRBs may provide little guidance to investigators, there has been much discussion in the literature of challenges and strategies for including IWCD in research and evaluation. Northway et al. (2014), in describing their process of receiving approval from an ethics committee to conduct research with individuals with ID as both participants and team members, suggest researchers need to anticipate potential concerns and provide a clear rationale for how accommodations will maintain the ethical standards.

Recruiting Participants

Researchers face several common obstacles to recruitment for studies with IWCD. Because IWCD often live their lives away from the mainstream, researchers can struggle to recruit a sufficient number of participants (Cleaver, Ouellette-Kuntz, & Sakar, 2010). Researchers have difficulty advertising their studies to potential participants who may be unable to read fliers or understand brief study descriptions provided by intermediaries. In their review of research with adults with ID conducted in Eastern Ontario over a 20-year period, Cleaver et al. (2010) learned that while participation rates varied from 41% to 100%, participation rates were over 90% for five out of six studies in which the researchers directly spoke with the participants. Swaine et al. (2011) and Lennox et al. (2005) both used information sessions to increase recruitment by allowing time to introduce the study in person and having time to answer questions from IWCD and their families. Swaine et al. used video and photographs to educate potential participants, women in post-secondary education programs, about the program being piloted in addition to reviewing details about consent and data collection. They found it was important to schedule these sessions in the evening to avoid conflicting with family work schedules.

Another commonly mentioned obstacle to recruiting IWCD is the presence of 'gatekeepers.' These are individuals who control whether or not the researcher is given access to the participant in order to obtain consent (Sherratt et al., 2007; Witham, Beddow, & Haigh, 2015). Gatekeepers, including group home staff, family, friends, and ethics committees, play an important role in the protection of vulnerable populations and can provide valuable information about an individual's capacity to consent (Hellstrom et al., 2007; McDonald, Keys, & Henry, 2008). However, they can also prevent IWCD who would have liked to participate from having the opportunity to be heard. These gatekeepers have been found to refuse access in cases where the institutional residents would have wanted to participate (Appelbaum, 2010). McKeown, Clarke, Ingleton, and Repper (2009) note that gatekeepers may be overprotective and deny individuals with dementia the right to make a choice about participating in research. Carlsson, Paterson, Scott-Findlay, Ehnfors, and Ehrenberg (2007) provide an example from their research:

> One family member of a person with TBI in Paterson's research indicated that she, not her significant other, would be interviewed because "he is too stressed right now with everything that is going on." Later, the injured person contacted the recruitment nurse and asked why he had been overlooked for the interview (p. 1364).

Gatekeepers may also prevent contact because of their own beliefs about the research, their relationships with the patient, and time constraints (McKeown et al., 2009; Appelbaum, 2010).

A study by Lennox at al. (2005) provides an example of the challenges with gatekeepers and other recruitment barriers that researchers face. In an effort to identify a sample of 1,000 individuals with ID for their study, Lennox et al. made three attempts to recruit participants. First, they contacted almost 200 organizations in the field, of which 62% agreed to participate and distribute information about the study to potential participants. However, workload and distrust of research by staff in the organizations resulted in many participants not being contacted. Second, the researchers attempted to have individuals who were known within the field or staff within organizations make phone calls to potential participants and inform them about the study. Finally, the researchers held multiple information sessions to answer questions about the project for potential participants and their families. In the end, the researchers still only recruited about a quarter of their target sample. The researchers found that complex management systems within large organizations made it difficult to gain the cooperation of staff, and the workload of staff in smaller organizations made assistance with recruitment challenging. Based on their experience, the researchers recommend allowing sufficient time and funding for locating and contacting potential participants, knowing the language of the disability organizations to avoid offending individuals, and, where possible, finding direct ways to access IWCD.

In another example of recruitment challenges, Becker, Roberts, Morrison, and Silver (2004) conducted a study involving individuals with ID in which their IRB did not allow direct contact of participants until they had expressed some desire to participate. They asked service providers and other stakeholders to distribute flyers about the study to potential participants. This strategy presented challenges since the participants had to read the flyer and call a number to participate or return the flyer with contact information. These requirements meant that some individuals who may have wanted to participate were excluded through the recruitment strategy. The researchers did go to some programs to present the study to potential participants, but program staff still needed to help many participants indicate interest in participating through the completion of the flyers. Although administrators of programs agreed to assist with recruitment, those tasks were delegated to other staff members who had no time or incentive to help with recruitment. Staff members also stated that the research was not helpful for their program and therefore did not want to assist with recruitment. The researchers discovered that potential participants had questions about the study that the staff were unable to answer. They recommend that researchers find staff members who are able to understand and explain the purpose of the study to IWCD.

McDonald et al. (2009) determined that there is not agreement among the researchers and IRB members they surveyed about the best recruitment strategies. Some participants felt that persons with ID should be approached by a known person who is trusted and can help them understand the study. However, others felt that it was important that a neutral representative introduce the study due to concerns about possible coercion and privacy.

One solution to identifying potential research participants with cognitive disabilities is through a registry of individuals who are interested in participating in research projects. Conners, Phillips, Rhodes, and Hamilton (2014) describe the development of a registry for individuals with ID and their families. The authors developed the registry by sending out brochures, posting fliers, and providing information at events attended by individuals with intellectual disabilities, their families, and other advocates. Family members provided consent to be listed in the registry, and the registry contacts were advised they did not need to participate in every study for which they were invited. Further, the researchers ensured that no participant was contacted more than three times a year. Conners et al. surveyed the contacts about their experience with the registry (n = 92) and found that 98% of their respondents joined because they wanted to support research on ID. The vast majority of contacts who participated in a study through the registry enjoyed the experience. The survey also showed that individuals may avoid joining such a registry due to lack of time, concerns about privacy, and the paperwork involved.

Obtaining Consent and Assent

The most discussed obstacle to participation of IWCD in research and evaluation is the process of informed consent. United States federal regulations require that informed consent be made by an individual or “legally authorized representative” (CFR 45, Part 46.116). To provide consent, an individual must be informed of the purpose, potential risks and benefits of the study, and must be able to consent on a voluntary basis, without coercion from others (Alzheimer's Association, 2004; Appelbaum, 2010; Carpenter et al., 2000; Cubit, 2010). Embedded in consent is autonomy or the right of individuals to make decisions about risks and benefits for their own lives (Simpson, 2010). IWCD may have never had or no longer have the capacity to consent for themselves. In cases where an individual has a cognitive disability and does not have a legally appointed guardian, the researcher must determine whether or not the individual has the capacity to provide voluntary informed consent (Iacono, 2006). Researchers face further complications when an individual with a mild disability, such as early stage dementia, lacks a diagnosis, chooses not to disclose his or her disability, or is in denial about the disability (Cubit, 2010). Cacchione (2011) notes that capacity is a judgment made by a clinician or researcher, whereas competency is determined by a judge based on two physicians' assessments.

Researchers emphasize the importance of ensuring that consent is voluntary, which can be difficult when working with IWCD (Anderson & Mukherjee, 2007; Freedman, 2001; Iacono, 2006). Reliance upon others, including family members, makes IWCD more vulnerable to coercion and influence. Participants should have consent collected by individuals who are non-care givers and who do not provide services for the individual. When an individual is dependent on the researcher in any way, such as when the researcher is a clinician, informed consent may not be voluntary, as the patient might be trying to please the clinician for fear of losing assistance. IWCD need to have researchers or advocates who are not involved in the treatment or services review consent with the patients. In their study with individuals with schizophrenia and bipolar disorder, Graor and Knapik (2013) ensured that the program staff would not know if the person chose to participate or not. In addition, they reduced the power differential by reminding the participants that they were valuable in the process. Data collectors are expected to continuously check for consent throughout the research process (Howe, 2012). Since there are no universal guidelines, researchers must clearly report how they made decisions about capacity to consent (Simpson 2010).

Assessing capacity to consent. As described by Appelbaum (2010) and Anderson and Mukherjee (2007), there are four components to having the capacity to consent. First, individuals must be able to understand the information that is provided about the research project. Second, individuals must understand the implications of participation. Third, they must be able to make a decision about participation based on the provided information, and fourth, they must be able to communicate that decision with the researcher. IWCD may have difficulty with one or more of these steps, reducing their capacity to consent.

There are a number of psychometric measures designed to assess capacity to consent, the most common and validated of which is the MacArthur Competency Assessment Tool for Clinical Research (MacCAT-CR, Howe, 2012; Simpson, 2010). The MacCAT measures four elements: understanding of information, developing opinions about the information, ability to choose between options, and ability to present a choice. Another common measure is the Mini-Mental State Exam (MMSE; Hougham et al., 2003; Simpson, 2010). These measures are generally semi-structured interviews or short orally administered surveys that are used while the researcher is providing consent information to the potential participant (Cacchione, 2011; Lamont, Jeon, & Chiarella, 2013; Simpson, 2010).

Several studies highlight the importance of screening measures for determining decisional capacity. Black et al. (2008) conducted a study on 198 Maryland residents with dementia who lived in 22 assisted living facilities. They found that 33% of the participants were able to provide written assent (unofficial agreement), 30% were able to provide verbal assent, and only 36% could provide informed consent. Those who could not provide informed consent required the help of a surrogate decision maker.

In another study, researchers conducted semi-structured interviews with 62 homeless individuals with developmental disabilities (IDD) in St. Louis, Missouri (Morton & Cunningham-Williams, 2009). During the interviews, the interviewer explained the study and consent process. The participants were then screened for capacity to consent and were given three chances to pass the screening. Results showed that most participants agreed that they understood the consent form, but 44% failed the screener on the first try, demonstrating the importance of careful screening for capacity to consent of IDD.

However, capacity assessments are not always useful. In their study of individuals with dementia and their spouses, Hellstrom et al. (2007) realized that the assessment they used did not correlate with the participant’s ability to communicate the information needed in the study. Instead, they found that the measure focused on deficits and was insulting for the individuals to complete. Hougham et al. (2003) note that many assessments are dependent on the individual’s verbal abilities and may eliminate individuals with such deficits who can otherwise make decisions and consent. In a review of 19 instruments published from 2005 through 2010, Lamont et al. (2013) determined that few measures have exhibited sufficient validity and reliability. Most instruments had not been validated in multiple groups, nor had researchers examined their test-retest reliability.

Making consent accessible. Having a cognitive disability may result in difficulty making decisions, but those with mild or moderate disabilities may still be capable of providing consent (Appelbaum, 2010). Excluding participants because of the complexity of consent forms is discriminatory since in many cases project information can be simplified to the point that a person who is unable to understand complex documents is able make an informed decision (Sherratt et al., 2007). Individuals' competency should be assessed based on what the participants will be asked to do in the study (Hellstrom et al., 2007). For example, persons with dementia may be more competent to express feelings than remember facts. Some competency measures fail to take into account the purpose of the research.

Many studies have shown that making materials more accessible or providing additional education to the participants allows them to have capacity to consent. In a study examining capacity for consent of individuals with schizophrenia, participants with and without schizophrenia completed the MacCAT-CR (Carpenter et al., 2000). While the participants with schizophrenia scored worse on the measure, after an "education remediation intervention" was conducted over two 30-minute sessions in which participants reviewed the research protocol and common concepts in the research, scores were equal to the comparison group of college freshmen.

Fisher (2006) conducted a study with 100 individuals with mild or moderate ID and a control group of 50 college freshmen without ID. The participants responded to consent questions for a hypothetical clinical trial. The researchers read consent information in short sections, followed by questions that were phrased to avoid responses based on memorization. Fisher found that many of those with mild ID had the capacity to consent. They were able to make a choice and understand the consequences of that choice. Participants had more difficulty understanding the purpose of the research and describing reasons for or against participation. Almost all participants with mild ID scored in same range as the control group, and over a third of adults with moderate ID scored in that range, higher than expected. Fisher suggests the high rates of capacity are a result of the simple language used on the measure.

In focus groups conducted with individuals with mild intellectual disability, their care-takers, and others involved in providing services to IWCD, Andre-Barron, Strydom, and Hassiotis (2008) found that participants agreed that consent information needs to be made more accessible, particularly by addressing difficult terminology. Some attempts to make consent information accessible, such as including pictures, seemed to be more of a token than truly helpful. They suggest using multiple strategies for conveying the information, although they acknowledge that such strategies would require more time, resources and funding, further complicating researchers' attempts to include IWCD.

An example of a study including women with ID, Swaine et al. (2011) presented consent forms with short clear blocks of information accompanied by pictures and read the information aloud to potential participants. After working with the ID and guardians to gain consent, they realized that some of the guardians also found the simpler forms helpful and therefore provided simplified forms to everyone. The study demonstrates that increased educational intervention can help IWCD have the capacity to consent. Hurtado, Jones, and Burniston (2014) also found that participants were better able to understand consent when a leaflet with pictures was shown and explained. However, the presence of text in the leaflet did not improve comprehension, even for participants with mild ID.

Additional strategies have been suggested by other researchers. Murray (2013) and Howe (2012) also suggest that other formats be used to present consent information, such as pictures, video, or music. Furthermore, a positive relationship with the researcher may help increase understanding, and a negative relationship may decrease it. Researchers should attend to the emotional aspects of providing consent, such as feelings of fear, paranoia, or hopelessness the individual may have (Freedman, 2001; Taua, Neville, & Hepworth, 2014). A conversational tone should be used to provide comfort and time for the individual to ask questions. Individuals need to be able to retain information long enough to make a choice, but information can be broken into smaller segments to reduce the impact of memory issues on consent (Murray, 2013). The Alzheimer's Association (2004) recommends that researchers present the consent information both in writing and verbally. Their guidelines do not specify a particular measure for determining capacity. Hougham et al. (2003) found that researchers tend to focus on the family members instead of the potential participant when giving consent information, making it more challenging for the participant to understand the process.

However, accommodations may not always work as expected. Dye, Hare, and Hendy (2007) conducted a study with individuals with mild or moderate ID on their capacity to consent. The participants were presented an information passage written in simple language in one of three ways, and then asked a series of questions to check for understanding. One third of the participants had the consent passage read to them twice. Another third had the passage read once, then read again in three separate sections. The final third of participants had the passage read twice and had six photographs shown with the text. The researchers found that while all of the 85 participants who completed the study were able to indicate a choice, 69% understood the impact their choice had, and only 12% understood the nature of the study. The researchers did not find a difference between the participants who had pictures used with the passage or when the passage was broken into sections, presumably requiring less memory ability. The researchers acknowledged that participants may have performed better if the research was on a topic that was already familiar to them. The instrument in this study also focused on recall rather than actually measuring comprehension.

Dewing (2007) describes a process consent method that is arguably more inclusive than the traditional competency-based method. The process includes five elements: (1) preparing and obtaining background information, such as who helps the patient make decisions, determining when the patient is doing well, and knowing a little about them ahead of time; (2) determining capacity to consent using a range of options, such as how the person usually consents to other activities; (3) obtaining initial consent; (4) obtaining ongoing consent; and (5) getting feedback and support from staff. For example, the staff might notice if a participant is unhappy after participation and can help the researcher understand certain behaviors.

Surrogate consent. In situations where an individual is not capable of consenting, a surrogate (proxy) decision maker is often used to determine consent. Yarborough (2002) discusses three different types of proxy consent processes: subjective, substituted judgment, and best interests. The subjective consent is considered most ideal as it allows the proxy to only make decisions based on prior decisions of the patient. This includes decisions made in advance research directives. Best interest consent occurs when the decision is made by what the surrogate believes is in the best interest of the patient. The substituted judgment consent is between the two, and the proxy attempts to infer based on his/her knowledge of what the patient would decide in the situation. Yarborough states that “this kind of surrogate consent maximizes the chances to acknowledge the subjects’ status as person. Even though these adults with dementia may no longer be rational agents, we can still engage them personally, albeit indirectly, on the level of their individuality through their life narratives” (p. 166).

Researchers and others have expressed concerns about the use of surrogates to obtain informed consent. Care-givers may have other motivations than what the IWCD desire, and researchers must be aware of these differences (Black et al., 2010). Sometimes surrogate decision makers who should be making substituted judgment make decisions based on what they believe is in the best interest of the individual rather than what they believe the individual would have wanted. Overton et al. (2013) conducted surveys and interviews with 25 proxies about a hypothetical research scenario of a drug trial for Alzheimer’s disease. Participants mentioned that when discussing decisions with individuals, they tend to look for indicators of assent rather than dissent and were sometimes willing to override the patient’s preference if they felt it was in the patient’s best interest. One explanation for this decision was the changes Alzheimer’s patients have in lucidity day to day, so they assumed the individual would change her mind. Care-takers were also aware that they could persuade the patients in one way or another. Participants wanted to act in the best interest of the patients and protect them from potential harm. One participant mentioned overriding the mother’s dissent because the research was in her best interest and that of society. Of course, the results of this study may have differed if the case was not hypothetical.

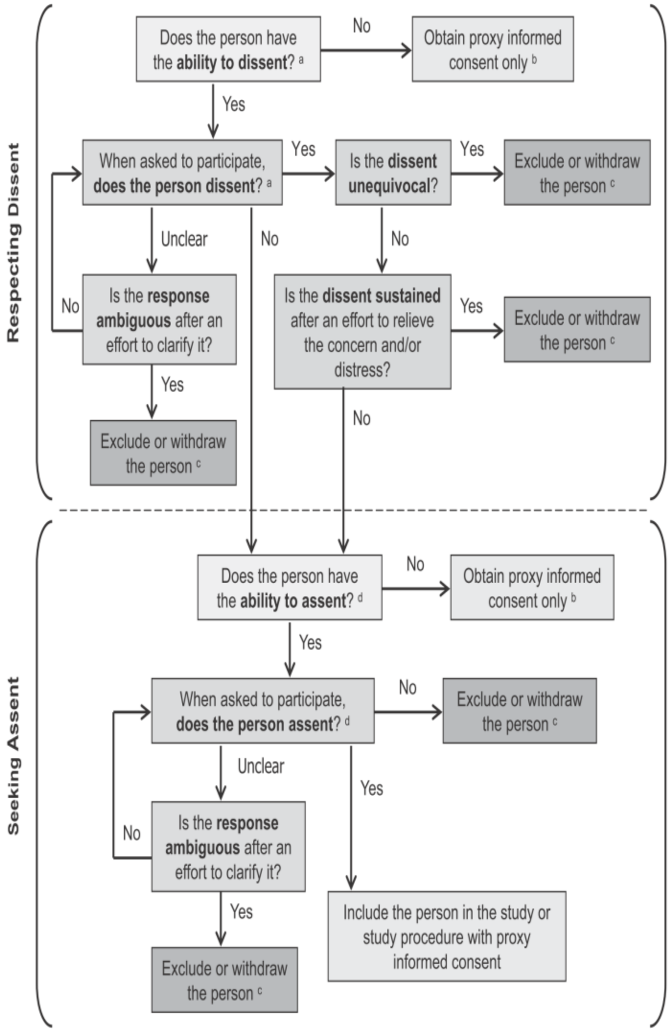
In another study, researchers held a day-long session with 160 adults 50 years and older about the use of surrogate consent and advance directives for dementia research (De Vries et al., 2013). Conversations at tables with 5-7 participants were recorded and coded. The participants were in strong support of surrogate consent, both for the benefit of patients and society, but also felt that assent should be obtained when possible and felt that surrogates should also be screened by interview to ensure they are acting on the patients' behalf and not their own. Participants were concerned that what they decide in advance directives is no longer relevant to the situation that requires consent.

Anderson and Mukherjee (2007) describe similar concerns about advanced directives. Since the participant cannot know exactly what type of discomfort might occur in the future and how he or she will respond, advance directives might not always be considered informed consent. The IWCD could express wishes that contradict the directive, leaving the researcher or IRB to determine if the dissent should override competence consent. Stocking et al. (2006) interviewed 149 patients with dementia and their family proxies about their preferences for future research participation in hypothetical projects. The majority of the patients (83%) preferred to have their proxies make their consent decisions rather than completing an advance directive for research. Even 46% of the patients who had expressed discomfort with the idea of a proxy making decisions about research still preferred that the proxy decide, although African-American patients were less trustful of the proxies. The researchers suggested that these results should reassure researchers who need to use proxy consent, but caution that a fifth of the participants preferred using advance directives.

Researchers generally agree that, when possible, assent should be sought from the participants, even if the participant has a legal surrogate. In a series of interviews and focus groups with 40 university-based experts on dementia and research ethics, participants described important characteristics of assent and dissent (Black et al., 2010). The participants agreed that both assent and dissent should be open categories that allow for a variety of communication, including verbal and behavioral, but that the individual must show some ability to understand the information and make a choice. For example, IWCD may express assent by smiling in response to questions around consent. Dissent may be expressed by a flat affect in an individual who otherwise smiles.

The participants further agreed that dissent is binding if clear and unchanged after attempts to alleviate concerns about the project or external factors that may be causing distress (Black et al., 2010). If an individual is unable to provide assent or dissent, he or she should still have the opportunity to participate in the research at the surrogate decision maker’s discretion. The participants agreed that whenever the person with dementia has the ability to assent, assent must be required, even if the surrogate has already consented. Using these results, the researchers developed a decision tree, shown in Figure 1, which explains the options a researcher has when seeking assent.

These recommendations align with those of the Alzheimer’s Association panel (2004). In cases where the answer is unclear, such as for individuals with aphasia, the panel recommended the researcher work with a caregiver who is knowledgeable about how the individual communicates (Black et al., 2010). Contrary to the results of Overton et al. (2013), the participants felt that consent by a surrogate should not override dissent by the individual. The participants were not in agreement as to whether or not lack of objection could be considered assent.



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a: Dissent (decline to assent)—an expression or indication of unwillingness to participate in the study or study procedure. b: Obtain proxy informed consent only, if acceptable to the institutional review board. c: Exclude or withdraw the person from the study or study procedure. d: Assent—an affirmative agreement to participate in a study or indication of willingness to cooperate with a study procedure.

Figure 1. "Decision Tree for Respecting Dissent and Seeking Assent for Dementia Research," by Black, B. S., Rabins, P. V., Sugarman, J., & Karlawish, J. H. (2010). Seeking Assent and Respecting Dissent in Dementia Research. *The American Journal of Geriatric Psychiatry*, *18*(1), 77–85.

Slaughter et al. (2007) also developed guidelines for obtaining consent from a proxy and assent from the participants with dementia in their study. The proxies were contacted by staff using a script asking if they would be interested in speaking to the researcher about the study. The staff knew who the legal decision maker was for each patient or contacted the family member or whoever usually made medical decisions for the patient. The researchers obtained consent from everyone if there were multiple decision makers. If there was no one available to contact, the patient was excluded from the study. When trying to obtain assent, if the patient said no, the researcher spent some more time talking with him or her. If the patient still said no, the conversation was ended, and the researcher asked the facility if the patient was having a difficult day and for suggestions on a better approach. Usually, the researchers would approach the person again on a different day. If the patient still refused, the patient was considered to have dissented. Assent was continuously obtained throughout the interviews. If the patient became uncomfortable, the interview was ended and assent was requested again.

Data Collection and Analysis

While recruitment and consent can be major hurdles for researchers and evaluators who are including IWCD as participants, data collection and analysis can also present difficulties. Much has been written on the different methods for collecting data from IWCD. This section presents a review of the literature around qualitative and quantitative methods and the use of proxies for data collection.

Qualitative methods. IWCD have often been excluded from qualitative research, particularly interviews, because they cannot clearly reflect on their experiences and articulate their views (Carlsson et al., 2007; Lloyd, Gatherer, & Kalsy, 2006). Because

IWCD may not have their views heard as regularly as others, it is important for researchers to find ways to include these individuals in qualitative research and not penalize them for having a disability (Cheston et al., 2000; Lloyd, Gatherer, & Kalsey, 2006). IWCD can have difficulty understanding complex ideas and phrases and may have trouble explaining their views related to a particular context. IWCD may also have difficulty recalling events or even words.

Lloyd et al. (2006) conducted a literature review on the use of qualitative interviews with individuals with a range of communication disabilities, including dementia, ID, aphasia, and traumatic brain injury, and found that while researchers have increasingly included these individuals as interview participants, the majority of research has occurred with individuals whose disabilities are mild, such as early to mid-stage dementia. Lloyd et al. point out the challenge researchers have of determining whether a participant's responses are limited by his or her communication difficulties or lack of understanding of the issue.

Conducting qualitative research with IWCD requires revisiting the key tenets of quality data (Carlsson et al., 2007; Lloyd et al., 2006; Sigstad, 2014). For example, qualitative data from IWCD may consist of short, disconnected, and vague phrases rather than the rich statements generally desired by researchers (Lloyd et al., 2006; Sigstad, 2014). While researchers generally prefer that the interviewee does most of the speaking and limits prompts to avoid biasing the data, IWCD, particularly in cases of aphasia, may require help thinking of words. Another important component of qualitative research is having participants review their contributions to ensure accuracy in summary and interpretation, also known as "member checks" (Finlay & Lyons, 2001; Lloyd et al., 2006). Individuals who have difficulty with comprehension and recall have difficulty providing such confirmation (Moyle, 2002). Moyle provides an example of two participants with severe depression who were unable to recall speaking with the interviewer at the end of the interviews.

Luck and Rose (2007) shared their experience and strategies for interviewing five males with chronic aphasia in a pilot study about improving the services of the Australian Aphasia Association. Because individuals with aphasia often use other means of communication, such as gestures, drawing, and writing to compensate for limited verbal skills, the researchers used video recording instead of only audio for the interviews. The researchers began the interviews by discussing strategies that the participant found helpful for communication. In the first interview, the researchers followed the traditional interviewing technique of not helping the participants think of answers for fear of biasing the interview. However, after obtaining little useful information, the researchers decided to help facilitate the interview by offering words, probing for additional information to narrow responses, and using encouraging sounds to let interviewees know they were being understood. For analysis, the researchers recommend meticulously recording decisions about interpretations of the data and had 20% of the videos reviewed by an expert on aphasia, in addition to other sections that were difficult to interpret. They separated responses that were clearly independent from those that were influenced by the interviewer.

Bronken and Kirkevold (2013) also supported their participants during interviews in a study with 25 individuals with mild to severe aphasia. As with Luck and Rose (2007), the researchers facilitated the conversation using techniques including prompting and offering words. In more structured questions, they provided possible answers in writing for the participants to point to, believing this would reduce the burden of having to respond verbally. One participant could not recall what he had told the researcher and was concerned by this. The researcher needed to remind the participant to help him keep track of what he was saying. In analysis, the researchers found clarity by piecing together fragments of information provided during different interviews and recommended that data collection occur longitudinally rather than in one instance. These researchers also video-recorded the interviews to allow for the inclusion of non-verbal communications.

A common issue for researchers interviewing individuals with ID is acquiescence or the tendency to say yes to whatever question is asked (Finlay & Lyons, 2001, 2002). Finlay and Lyons (2002) suggest that while sometimes participants are trying to please the researcher, acquiescence can also be the result of questions that are too grammatically or conceptually complex for the individuals. The authors provide several recommendations for presenting clearer questions when interviewing individuals with ID, including using “either/or” rather than “yes/no” questions, using simple language, and allowing respondents to say they do not know when responding to questionnaires. IWCD may also have difficulty answer questions about time, unless concrete events are used to improve recall (Finlay & Lyons, 2001; Hubbard et al., 2003). Using these questions along with open-ended questions allows the IWCD to express a fuller range of views (Cheston et al., 2000). For IWCD, interview protocols need to include open-ended questions that have a clear, short structure and avoid complex concepts (Finlay & Lyons, 2001; Lloyd et al., 2006).

The use of multiple qualitative methods can allow researchers to be more inclusive (Hubbard et al., 2003; Lloyd et al., 2006). Hubbard et al. conducted an ethnographic study on quality of life in an institutional care facility and used a combination of interviews and observations with individuals with varying degrees of dementia. During an initial visit with the participants, the researchers determined if the participants would be able to participate in an interview. They determined that if the individual was able to answer questions clearly and logically, he or she would be interviewed. The interviews and observation sessions lasted from 30 minutes to 2 hours. During the observations, Hubbard et al. approached the participants and asked them to explain their actions.

The researchers found that communication and cognitive ability changed from day-to-day and upon reflection realized they should have been more flexible in data collection schedule so that they could have spoken with the participants when they were more lucid (Hubbard et al., 2003). As with Bronken and Kirkevold (2013) and Luck and Rose (2007), the interviewers stepped in to help in cases where the participants were embarrassed about what they had said or when they were having difficulty expressing their thoughts. Hubbard et al. explained, “There is need to develop a strategy whereby the voice of the person with dementia is privileged but whereby the participant is also supported” (p. 357). These authors and others (Carlsson et al., 2007; Moyle, 2002) agree that when collecting qualitative data, the researchers should be experienced in working with individuals with communication difficulties.

Bronken and Kirkevold (2013) also used multiple methods by supporting their interview data with participant observations, which provided additional details about the experiences of the participants. Ware (2004) cautioned researchers from using solely observations to make inferences about an individual’s desires. Ware uses the example that a person may react negatively while getting a tooth filling, but still want to have a filling done if her tooth hurts. Similarly, Van Baalen, Vingerhoets, Sixma, and de Lange (2010) compared different methods in a literature review on including individuals with dementia when researching quality of care and determined that while observation may be an appropriate method for all levels of dementia, the observer cannot know if participants believe certain activities are important to the quality of their care.

Dalemans, van den Heuvel, and de Witte (2009) conducted a qualitative study with 13 individuals with aphasia and their primary care-givers to explore how they view social participation. The researchers used multiple research methods and made several accommodations for the participants, based on the severity and type of their aphasia. Some of the strategies these researchers used are contrary to those described above. The participants were asked to complete a pre-structured diary on their own time. The researchers theorized that by removing the stress of time, the individuals would be better able to express themselves. The diary asked about activities and performance on those activities and included pictures and space for the care-givers to provide their own comments. The researchers noted that the participants completed information about their activities, but said little about their performance. The method of using questionnaires is supported by van Baalen et al. (2010), who found that the use of self-administered questionnaires provides privacy for the participants and is less expensive for researchers, but cognitive difficulties make this method challenging for some participants.

Dalemans et al. (2008) conducted interviews with the participants and included the care-givers for support as well as interview assistants. In contrast, Bronken and Kirkevold (2013) interviewed the individuals without the presence of a care-giver whenever possible to avoid others speaking for the participants, which happens frequently for individuals with aphasia. McDonald (2012) found that participants felt it was important for interviews to take place in private, away from care-givers. Dalemans et al. chose to audio-record the participants, fearing video would make them more nervous, and the interview assistant was there to note gestures and facial expressions used by the participant. The interviewer directed questions to the participant first, then to the care-giver. Questions were short with simple phrasing, and pictures were used to enhance clarity. In situations where no one was able to understand what the participant was trying to communicate, the topic was put aside and reintroduced later in the interview after tension had subsided. The interviewers occasionally needed to stop the care-giver from over-powering the participant. Other authors support the inclusion of diagrams when collecting data with IWCD, including specific tools such as talking mats and photo-voice (Boxall & Ralph, 2009; Carlsson et al., 2007; Jurkowski, 2008)

Finally, Dalemans et al. (2008) conducted focus groups with participants and care-givers, which included a presentation of previously collected data. A report was also provided in advance to allow participants to review the data. The researchers reported that the participants were active in discussions and reported no difficulties with the focus group. In Van Baalen et al.'s (2010) review, focus groups were seen as a beneficial way to have participants share their views and hear the experiences of others, which can serve to remind the individuals of their own experiences. Conder, Milner, and Mirfin-Veitch

(2011) found that while focus groups were effective for most people in their study with people with ID, there were some individuals who did not speak and may have participated more fully in an individual interview.

Fatigue. Reflecting on their experiences interviewing adults who have suffered stroke or traumatic brain injury, Carlsson et al. (2007) explained that interviews with individuals with communication difficulties can cause fatigue for the participants. They recommend that interviews need to be kept to short increments, unlike the 2-hour interviews conducted by Hubbard et al., (2003). While participant fatigue is possible with quantitative methods, the level and amount of communication required in qualitative data collection makes it a particular concern for researchers. As participants begin to become fatigued by trying to communicate, they may misinterpret questions and their communication may become even less clear. Answers can be fragmented and off topic, and participants may need the questions to be repeated multiple times before they are able to provide a complete answer. McDonald's interviews of individuals with ID revealed that they "become confused, frustrated, develop headaches, or lose interest when research is too lengthy" (p.268). Dalemans et al. (2008) provided short breaks when the participant began to show signs of fatigue, generally after about 15-25 minutes. Individuals with dementia may have more difficulty communicating later in the day if they experience "sundowning," or an increase in confusion, anxiety, or agitation as the day progresses (Khachiyants, Trinkle, Son, & Kim, 2011).

Researchers may also become fatigued during the process because of the level of attention required to prompt, listen for contradictory statements, piece together disjointed statements, and interpret gestures and facial expressions during the interview process

(Bronken & Kirkevold, 2013; Carlsson et al., 2007; Moyle, 2002). Researcher fatigue can lead to missing needed prompts and important signs of participant fatigue. When interviewing individuals with major depressive disorder, which can also cause disordered thoughts, problems with distorted memories, and memory loss due to treatments such as electroconvulsive therapy (ECT), Moyle described a "contagion effect," which can lead to the interviewer feeling sad, angry, or tired. Moyle suggests that interviewers debrief with a mentor after completing such interviews.

Quantitative methods. As with qualitative methods, researchers have modified quantitative methods to make them more accessible and reliable. Several of the strategies for collecting quantitative data were mentioned in the previous section, and the common strategies for both quantitative and qualitative methods are summarized in Table 1. Dalemans et al. (2009) conducted a quantitative study with 128 individuals with aphasia. After assessing their communication abilities using the Frenchay Aphasia Screening Test (FAST), the researchers selected an instrument that used simple language, included supporting images, provided a small number of answer choices, and was short in length. They further edited the instrument to use a large clear font (e.g., Verdana, size 16), bolded key terms, further simplified the questions, and added space between them. The questionnaire was administered in interview format by an interviewer who had reviewed the FAST results prior to meeting with the participant. When asked about the questionnaire, all participants found the bolding and pictures helpful. When participants looked as if they did not understand a question, the interviewer restated it. Although these changes are normally considered to reduce the reliability of the data, the changes were necessary to make the research more inclusive.

Table 1

Inclusion Strategies and Accommodations for Common Data Collection Methods

Method	Possible strategies and accommodations	Source(s)
Interview	Provide prompts and words; Video-record to capture gestures and facial expressions; Allow participants to write, draw or point to images; Reassure participant of your comprehension; Conduct interviews over multiple sessions; Use simplified language; Take frequent breaks	Bronken & Kirkevold, 2013; Hubbard et al., 2003; Lloyd et al., 2006; Luck & Rose, 2007; Sigstad, 2014
Focus group	Provide the option of individual interviews; Provide information in advance	Conder et al., 2011; Dalemans et al., 2009
Observation	Ask participants about their actions	Hubbard et al., 2003
Questionnaire	Conduct survey in person; Avoid yes/no questions to prevent acquiescence; Limit options for Likert-type items; Avoid questions that require recall; Avoid complex ideas; Use simplified language; Use images to help clarify questions; Limit questions to one per page; Use large, clear font	Dalemans et al., 2009; Finlay & Lyons, 2001, 2002; Hartley & MacLean, 2006; Tucker et al. 2011

Tucker, Edwards, Mathews, Baum, and Connor (2011) examined how quantitative measures could be modified for 29 individuals with mild to moderate aphasia. The participants needed to be able to participate in 2-3 hours of testing, be able to self-report, and travel to the testing center. The researchers modified several common measures in similar ways as Daleman et al.'s (2009) by modifying the format of the measures, such as producing one question per page, increasing font size and spacing, and splitting a photo sorting activity into smaller segments.

The researchers also developed a protocol for the examiner to provide support to the participants (Tucker et al., 2011). The protocol allowed the examiner to try up to 5 sequential strategies to assist the participant: 1) Restate the question and answer choices, 2) rephrase the question more simply, 3) review the answer choices with examples, 4) convert a scale question to multiple yes/no questions, and 5) move on to the next question. Participants were rated on a 7-point scale based on the amount of support they needed. Results showed that 21% of the participants required no assistance, and only 12% required full assistance on the measures. Although this study demonstrates that effective modifications can be made to measures for individuals with aphasia, the study used a convenience sample of individuals with mild aphasia, and these strategies may not be effective for those with more severe communication difficulties.

Hartley and MacLean (2006) conducted a study to assess the reliability of Likert-type items when used with individuals with ID. They reviewed 51 studies published between 1979 and 2005 that used Likert-type items with individuals with developmental disabilities. When examining response rates for these items in comparison to other question types, they were comparable. When comparing response rates for Likert-type items with 3, 4 and 5 options, again no differences were found. The researchers did find differences in response rates based on the level of disability. Studies that included pictorial assistance had higher response rates. Participants also had higher response rates when the forms used simple labels such as “never” and “often” rather than more complex self-descriptive statements such as “I have as much energy as ever” (p. 816). The researchers found that response bias, the tendency to choose the most positive response, was more common among lower intellectually functioning participants. Allowing interviewers to paraphrase questions for participants also reduced response bias. These findings suggest that Likert-type items can be reliable when used with individuals with ID and can be an efficient method for collecting self-reported data. Many of the studies included in this analysis were conducted on individuals with mild ID. To the contrary, Finlay and Lyons (2001) found that Likert-type items presented difficulty for individuals with ID and should be avoided. Conder et al. (2011) and Brooks, Davies, and Twigg (2013) found that individuals with ID struggled with 5-point scales.

Participation by proxy. When IWCD have difficulty communicating their experiences, researchers often use proxies, such as family, friends or care-givers to respond for the individual (Cheston et al., 2000). Research is mixed on the extent to which proxy responses are representative of the participants’ experiences and on whether a close relationship between the proxy and participant produces more or less reliable data, although generally these variables depend on each study (Cheston et al., 2000; Cusick, Gerhart, & Mellick, 2000; Stancliffe, 2000). Researchers emphasize that whenever possible, information should be obtained directly from the participant (Claes et al., 2012; Cusick et al., 2000). The use of proxies has the benefit of allowing individuals who would otherwise not be included to have their experience shared in some way and allows researchers to increase sample size (Cusick et al., 2000). Stancliffe (2000) argues that “the use of proxies can be justified when the questionnaire used is known to possess empirically well-established consumer: proxy agreement” (p. 90).

Several studies have examined the reliability of proxy responses. Claes et al. (2012) conducted two studies examining the reliability of support staff proxies who knew the participant for at least 3 months and family proxies on a quality of life questionnaire. The questionnaire consisted of 48 open-ended items and was administered in an interview format. Individuals with ID completed the interviews themselves, and the proxies completed the interviews by observing the participant. The results of the first study showed poor correlations between the staff proxies and participants on three of the eight domains measured. The second study showed poor correlation between staff and participants on two domains, but strong correlation between the family proxies and participants on all domains. However, the participants tended to rate themselves somewhat higher on the scale than did family members. The authors suggest that the individuals with ID compared themselves to others with ID rather than individuals without disabilities, as the family might have.

In a similar study, Cusick et al. (2000) researched the reliability of proxy ratings on three different community integration measures for 204 individuals with moderate to severe TBI. The participants selected their own proxies, and questionnaires were administered by telephone. The results showed that 87 percent of the items on the measures had high correlation between the proxy and participant, but that correlations were lower on questions about cognitive capacity, money management, and non-home based activities. They also found that participant-proxy correlation was equivalent to test-retest correlations. Proxies had a tendency to over-rate the impact of the TBI when the participants had mild injuries and underrate the impact when there were more severe injuries. In another study, Cusick, Brooks, and Whiteneck (2001) found that proxies tended to over-rate the level of mobility for individuals with severe cognitive disabilities and overall had lower correlation on community integration outcomes when the cognitive disability was more severe. Cruice, Worrall, Hickson, and Murison (2005) showed that proxies tend to have higher correlation on more objective measures than subjective.

Another study assessing individuals with intellectual disabilities' scores on a quality of life measure compared staff proxy and participant scores (Perry & Felce, 2002). While the other studies showed some correlation between proxy and participant scores, this study showed no significant correlation. The authors note that such findings are common for satisfaction measures. Other researchers examined the correlation between participants with TBI and their significant others (partners, family, or friends) on their participation in economic, community, and social activities (Hart et al., 2010). They also measured satisfaction with participation in these activities. The results showed higher correlation with the economic and community domains than the social domain and questions on satisfaction. The researchers discovered that when the proxy and participant spent time together on a daily basis, they had much higher correlation than those who spent less time together. The researchers did not find a difference in correlation when they compared different degrees of TBI.

Reporting

The final step to making the research process accessible to IWCD is through reporting, although this step has received less attention in the literature (Balandin, 2003). Results have been communicated to research participants through visual presentations as well as with clear, simplified summaries (Boland, Daly, & Staines, 2008). One way of making results accessible to IWCD is through simplified abstracts in journal articles, as is now done in the *British Journal of Learning Disabilities* (see Brooks, Davies, & Twigg, 2013). IWCD have the right to know the results of the studies in which they have participated and feel their contributions are appreciated, and they may appreciate a sense of closure (Balandin, 2003).

Inclusion as Advisers and Researchers/Evaluators

Inclusiveness in evaluation and research ranges from IWCD as participants in data collection to active participation of IWCD on the evaluation design team itself (Linhorst & Eckert, 2002). There are several approaches to inquiry that have facilitated IWCD participating in the full process of research and evaluation, from the inception of the idea, design, to completion of the study. These approaches are known as inclusive, participatory, emancipatory, and transformative. While there are subtle differences among some of these approaches, they all focus on including individuals as more than participants, i.e., to some degree including them in the research design. These approaches are often described interchangeably and will therefore be addressed together. For example, Johnson (2009) considered inclusive research to include both participatory and emancipatory approaches, and emancipatory research, as well as some participatory research, is considered transformative (King, Cousins, & Whitmore, 2007). The main distinction among these approaches appears to be the degree and purpose of the participation. Emancipatory/transformative evaluations attempt to restore power, while participatory evaluation focuses on producing more valid results and increasing use of the results. The majority of literature on these approaches comes from the intellectual disability field, although the ideas and techniques could likely be carried over to other disability groups. This section provides a description of these approaches along with some examples of their implementation on research with IWCD.

Inclusive research allows IWCD to have their voices heard, giving them the power to affect programs and society as a whole. Increasing individuals with cognitive disabilities' participation in research on issues relevant to them can thus further their inclusion in their communities (Johnson, 2009). As described by Johnson, inclusive research "is based on values and ideas which strongly emphasise [sic] the importance of research arising from the expressed interests and issues of people with ID, and in which they are involved not as sources of information or data, but in a research capacity" (p. 251). In inclusive research, the individuals with disabilities (IWD) are invested in the issue being studied, and the results will contribute to their interests. Furthermore, IWD have some power in the research process, and the results are accessible to IWD. Because inclusive research serves the interests of IWD, it can be a stepping stone toward collective action on a disability issue.

Inclusive approaches to inquiry arose to counter the traditional, positivist approach to research in which there are clear boundaries between the researcher and the subject (Barton, 2005; Oliver, 1992). Oliver explains,

> The social relations are built upon a firm distinction between the researcher and the researched; upon the belief that it is the researchers who have specialist knowledge and skills; and that it is they who should decide what topics should be researched and be in control of the whole process of research production (p.102).

As individuals with disabilities have not benefited much from research that has been conducted on them, it has become clear that they should be the ones setting the research agenda, not the researchers. The use of emancipatory and participatory approaches continue to grow in disability research (Barnes, 2003; Campbell, 1997; Gilbert, 2004).

The emancipatory approach strives to restore equality in society and facilitate the process of self-empowerment (Barton, 2005; King, Cousins, & Whitmore, 2007; Mertens, 2005; 2009; Oliver, 1992). Pure emancipatory research has the IWCD initiating the study, obtaining funding, designing the research, and selecting the research team (Boland et al., 2008). Strategies for emancipatory research include using a steering committee of IWCD to plan the research and hiring researchers or evaluators with disabilities (Boland et al., 2008; Gill, 1999). The researcher’s role is to support IWD in achieving their goals by providing their knowledge and skills in the research or evaluation process. In contrast, participatory research (or practical participatory evaluation) does not focus on empowerment, but on the betterment of the study outcome, such as program improvement (Barton, 2005; Gilbert, 2004; King, Cousins, & Whitmore, 2007).

However, empowerment may also be encouraged in the participatory approach. Participants bring new perspectives that can change the course of the project, and they can guide the evaluation or research questions if they have some experience in research (Linhorst & Eckert, 2002). In a participatory action research project, Kramer, Kramer, García-Iriarte, and Hammel (2011) were less researchers than advisers who provided data in visual formats of data for groups of individuals with ID to analyze results and run meetings. The participants stated they felt empowered by the process and that the advisers were there to assist when needed, but were not the authority.

Mertens (2001) discusses the importance of inclusive evaluation practices in which evaluators spend time learning about and building trust with those in the disability community. Mertens suggests that evaluations should include participants with disabilities in the evaluation design through the dissemination processes to ensure the evaluation is addressing issues that are of importance to the disability community. By working with individuals with disabilities, the evaluator can learn to frame the evaluation questions to address the problems in society, not only with the individuals (Gill, 1999; McDonald et al., 2013; Mertens 2001).

In practice, the majority of emancipatory research has used qualitative methods that more fully capture participants' life experiences (Barnes, 2003). Examples of emancipatory and participatory research reveal challenges in determining the role of both the IWCD (co-researcher) and the researcher. Whether a paid staff member on a research team or a volunteer on an advisory committee, IWCD often need additional supports, such as training in research skills, transportation, and materials that are presented in clear, simplified language (Caldwell, Hauss, & Stark, 2008; Johnson, 2009). Walmsley (2004) reflected on the roles of the researcher and co-researcher in inclusive research. Sometimes the power differential is changed by changing the titles, for example, the researcher becomes the "enquirer" and the person with a disability is the "expert." However, the "expert" should not be expected to act as an expert on research methodology and will continue to need some support from the supporting researcher. The researcher who has been professionally trained must show restraint in allowing the IWCD to develop skills through practice and training (Brooks et al., 2013; Strnadová, Cumming, Knox, Parmenter, & Welcome to Our Class Research Group, 2014; Walmsley, 2004).

Researchers must ensure the role of the co-researcher is more than tokenism (Chappell, 2000). Gill (1999) suggests that the inclusion of individuals in the evaluation process should be more than nominal and that barriers that limit inclusion and roles of power should be eliminated.

Strnadova et al. (2014) are a research team that consists of 4 academic researchers and 4 individuals with ID who were planning to study the lives of older women with ID. The research team spent 15 weeks doing research training on topics that were relevant to their upcoming research, as well as getting to know each others' strengths and how to best work together. Everyone on the team had something to learn in these trainings; the researchers with ID were learning about the research process, they along with some of the academic researchers were learning how to use an iPad, and one academic researcher was learning about qualitative research. One researcher with a milder ID often served as a go-between between the other researchers with ID and the academic researchers, helping the academics to see when they needed to provide additional clarification. Although the academic researchers wanted to involve the researchers with ID from the beginning, the initial grant and need for ethics committee approval meant that the general study design was already set and the researchers with ID were only able to help refine the study design. The researchers with ID were indispensable for the development of the interview protocols, as the majority of questions were thought of by them, rather than the academic researchers who lacked the "lived experience." The researchers attributed the success of their project to taking the necessary time to develop trusting relationships with their colleagues.

Brooks et al. (2013) also described their experience with inclusive participatory research with IWCD. The project was to develop a psychological measure for evaluating therapy programs. The researchers realized that existing measures did not ask specifically about the experience of IWCD and wanted IWCD to develop a new measure. The research group included three researchers and five IWCD. The group spent initial meetings getting to know each other to develop trust. They then taped discussions of the IWCD about their experiences with cognitive disabilities, and from those the entire research group developed possible items from the measure. To pilot the measures, the IWCD used their knowledge of the disability community and enjoyed explaining the research to others. The research group continued working together to develop the measure, with the IWCD being guided and supported by the researchers. Although the process took time, the IWCD "felt empowered" by being able to work on a challenging social issue. The researchers struggled with their role at times, explaining, "The tension between the dual role of researcher and facilitator can be a difficult one to manage, and there were times when we struggled not to take over, yet there were equally times when this was necessary" (p. 8).

In a similar participatory research project in which IWCD were developing a quality of life measurement tool, IWCD were brought onto the project after the funder had approved a research plan, so there was less flexibility and room for influence from the IWCD (Conder, Milner, & Mirfin-Veitch, 2011). However, the team took a "strengths -based approach" and rather than expecting the IWCD to quickly learn to be researchers, they allowed them to work on the tasks they felt the co-researchers would be successful with, although they also reflected that they should have spent additional time early on discussing the strengths and goals of the IWCD. The co-researchers successfully ran focus groups, which were helped by their strong inter-personal skills, but the task of sorting the data and finding themes was particularly exhausting for them. The researchers noted that in the end they were really the ones directing the research and level of participation.

In another example of inclusive research, Bigby and Frawley (2010) conducted a 3.5-year study on community living and employed a co-researcher with an intellectual disability on a part-time basis. The research was more participatory than emancipatory, as the co-researcher had no ownership of the study and the questions. As with Conder et al. (2011), the researchers let go of the idea that they could train the co-researcher in all research skills in just a short time and realized the purpose of the co-researcher's presence was not to add another skilled researcher to the group, but to allow him to develop research and empowerment skills through experience. The researchers had to re-evaluate the supports the co-researcher had, as he had difficulties remembering tasks week to week and struggled with understanding written materials. Protocols and transcripts were modified into flipcharts with pictures and short statements. All of these examples follow the more participatory than emancipatory approach because the researchers remained in control of the research, although Brooks et al. (2013) had originally strived to conduct a more emancipatory project. It is possible that true emancipatory studies with IWCD exist, but have yet to be published in peer-reviewed journals.

Conclusion

This literature review provides an overview of how IWCD can be included in evaluations. Although most of the literature focused on research rather than evaluation, the strategies needed to develop accessible, ethical, and valid evaluations are the same. Many of the issues and techniques discussed, such as the use of imagery or proxies, can be applied at each stage of an evaluation. Likewise, much of the research here has been conducted on individuals with a specific disability, but the commonalities across the cognitive disabilities mean that the lessons are applicable in a variety of contexts. All of these studies have been conducted with a focus on IWCD. We still do not know how evaluators include IWCD in evaluations for the general population.

One theme that runs throughout the literature is the additional time, money, and other resources required to conduct inclusive studies. Funders of evaluation projects may not be prepared to support evaluators in developing inclusive evaluation, especially for evaluations of programs for the general public. Evaluators may face greater challenges and have more diverse experiences around inclusion of IWCD simply because they must conduct the best study possible for a specific program within fiscal constraints.

Chapter 3: Methods

For this dissertation study a sequential explanatory mixed method design was used to address the research questions. The study was completed in two phases. Phase 1 consisted of the development and distribution of surveys followed by preliminary data analysis. These quantitative data were used to gain an understanding of the degree to which evaluators include individuals with disabilities as participants or on the evaluation team and the extent to which evaluators consider these individuals when conducting program evaluations.

Phase 2 involved developing protocols for semi-structured interviews, conducting the interviews, and analyzing the interview data. The qualitative component provides in-depth understanding of how evaluators perceive the inclusion of IWCD and the barriers these evaluators face when trying to include them. After both sets of data were analyzed, they were cross-tabulated in the discussion to highlight the insights gained by integrating the qualitative and quantitative results (see Figure 2). A mixed method design provides a comprehensive description of IWCD inclusion in program evaluations through the use of quantitative data collection and the reasons why IWCD are or are not successfully included (Creswell & Plano Clark, 2011).

Phase 1: Surveys (Quantitative Method)

The researcher used survey questionnaires to gain a broad understanding of the extent to which evaluators consider and include IWCD in the evaluation process and how those individuals are included. The survey method allows for basic information on evaluation practice to be obtained from a larger number of evaluators than can be obtained through other research methods (Dillman, Smyth, & Christian, 2009). The survey was also used to help guide the development of the qualitative interview protocol in Phase 2 of the study.

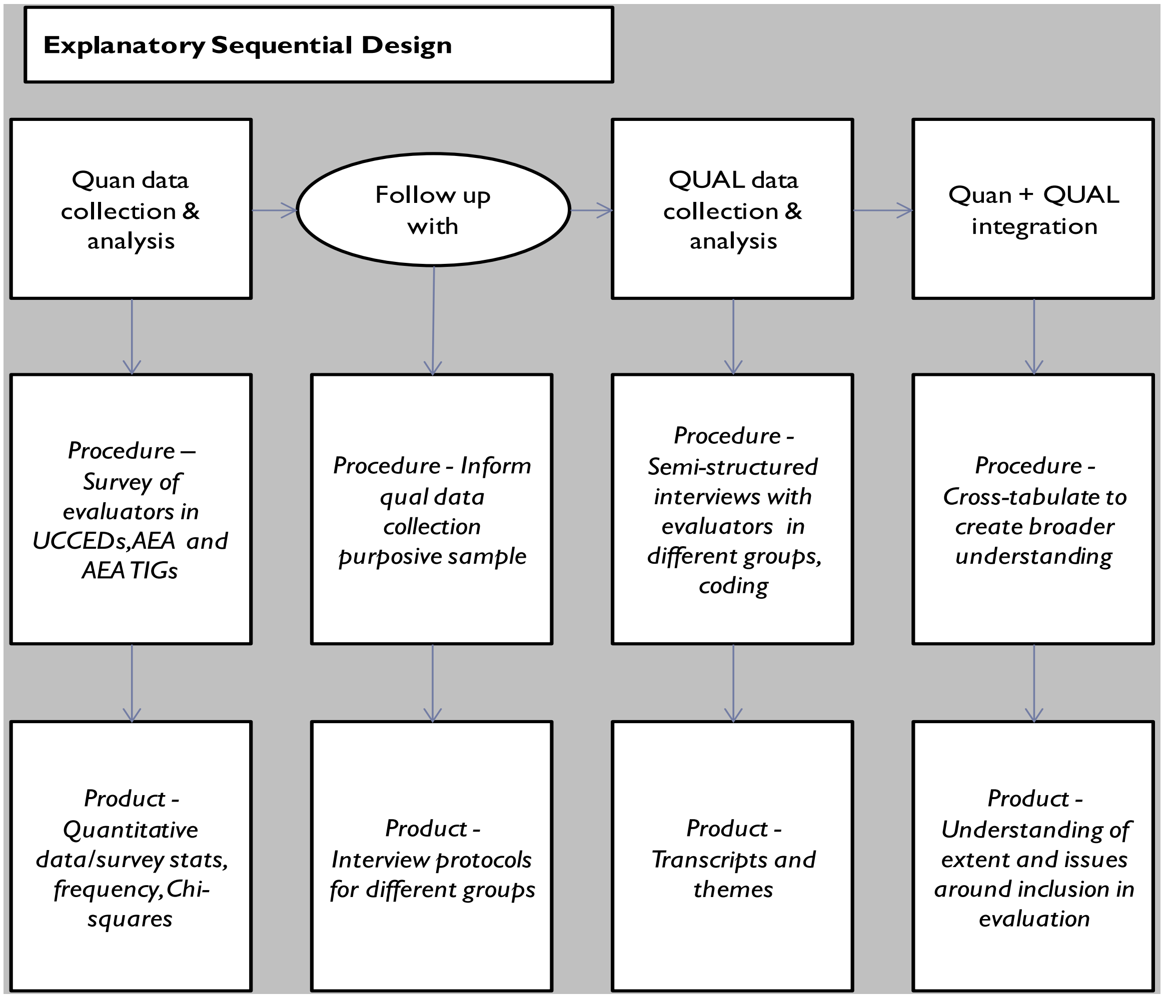


Figure 2. Explanatory sequential mixed method design diagram.

Instrument development

As no known measure of inclusion of IWCD in evaluations currently exists, the researcher developed the measure based on themes extracted from the published literature (see Appendix A).

Based on the literature and the researcher's evaluation knowledge, the questionnaire includes items about the participants' actual experiences in evaluation as well as their perceptions around these topics. The questionnaire also includes background questions about where the participants have practiced evaluation, years in the field, and educational background. Because the topics of participatory evaluation and culturally competent evaluation have been popular in the evaluation community in recent years, the background questions helped to identify which individuals were more aware of current discussions, which may have an impact on their responses.

During the questionnaire development, several considerations and actions were made to increase the rigor and validity of the measure. The questionnaire was developed using guidelines specified by survey method experts Dillman et al. (2009), Patten (2011), and Nardi (2006). For example, demographic questions were placed at the end of the survey, ordinal scales were carefully labeled, and fill-in "other" options were not included. These precautions helped to reduce measurement error, which Dillman et al. explain is "often the result of poor question wording or design and other aspects of questionnaire construction" (p. 18). Skip logic was used to keep the survey shorter and to prevent participants from answering questions that did not apply to their situation. Participants who had no experience collecting data from IWCD were asked questions about whether they ever considered such inclusion, and those with experience were asked several questions about the methods they used and how they viewed those evaluations. To avoid asking unnecessary questions, the question asking if the participant had ever worked in the evaluation field was removed from the questionnaires completed by participants who worked in one of the University Centers for Excellence in Developmental Disabilities (UCEDD).

To further insure that the questionnaire was clear and accurately interpreted by participants, the survey was piloted in a two-step process. First, five cognitive interviews were conducted with volunteer pilot testers in the Twin Cities metro area who had a range of experience working with IWCD in evaluations. During a cognitive interview, the researcher administers the survey to the pilot participants and asks the participants to think aloud as they answer each question (Dillman et al., 2009). Participants are encouraged to vocalize any confusion they have as they answer each question and to explain why answer options are or are not relevant to them. The process often reveals confusing language, missing options, layout problems, etc. The cognitive interviews were conducted in-person, and at the end of the survey, the pilot evaluators helped to workshop particularly difficult questions. After the first three interviews had been conducted, the survey was revised to address the identified problems. The researcher then conducted the other two cognitive interviews to further refine the questionnaire and test the modifications. Only minor changes were made after the final two cognitive interviews. The researcher revised most of the initial survey questions by the time the cognitive interview process was complete.

Second, the survey was distributed to 25 evaluators and evaluation students at and alumni of the University of Minnesota. Most of the pilot participants had no experience working with IWCD in evaluations. The researcher added an additional item to the questionnaire for these pilots asking the participants if they had any comments about the questionnaire. The pilot test showed that the answer options for each item were comprehensive, although a few minor changes were made based on the comments provided.

Because the questionnaire was the first to examine the issue of inclusion of IWCD in evaluation, no established criteria exist for measuring its concurrent validity. However, content validity was established by basing the survey questions on the current literature on evaluation and IWCD and by review of experts in the area of evaluation and disability. Content validity, or face validity, is “an equally subjective way to understand how well a set of items is measuring the complexity of a concept or variable we are studying” (Nardi, 2006, p. 59). These experts included a member of my dissertation committee and one other individual who has experience with IWCD and evaluation.

Sample

The survey participants for this study were selected from four groups: three from the American Evaluation Association (AEA), and one smaller group from the University Centers for Excellence in Developmental Disabilities (UCEDD). The AEA is a professional organization for evaluators that was established in 1986 and currently has about 7,000 participants, including approximately 900 student members. The association hosts an annual conference, the two flagship journals in the field, regular webinars, and active list-serves, among other activities. Members of AEA may belong to up to five of the 55 Topical Interest Groups (TIGs), which are groups of members with a common interest in a particular area or method of practice. The TIGs host conference sessions and sometimes provide other events or resources to members. The AEA participants include academics who study evaluation and professional evaluators who are interested in professional development and networking. Program evaluators exist in a wide variety of organizations, including academic institutions, government organizations, non-profits, foundations, and for-profit businesses. Many full-time evaluators are members of the American Evaluation Association, but not all are. Therefore, there is no directory or other way to identify the full population of evaluators from which to randomly sample. This study focuses primarily on the evaluation population at AEA.

The researcher submitted a research application to AEA detailing the purpose of the study and requesting a list of contacts from AEA's general membership as well as from the two TIGs. Upon approval from the AEA Board and each of the TIG directors, AEA provided the researcher with the names and emails of 1,000 randomly selected AEA general members and the entire membership of the two TIGs, minus students and any AEA members who had previously requested that they not be included in research study requests. AEA provided these lists on the condition that they would only be used for this study and that every email sent to AEA members includes a specific AEA statement informing participants that they may opt out of AEA research participation requests by contacting AEA. The AEA board further stipulated that the contact lists would expire after 30 days.

The first sample was taken from the general membership of AEA (the general group) and is representative of the evaluation population in terms of experience with inclusion. Although the general group is not a probabilistic sample of all evaluators in the United States and there are likely differences between those evaluators who are members and those who are not, the researcher used a random sample of AEA general members to ensure the sample is at least representative of AEA. Random samples are generally considered the gold standard in survey methods (Dillman et al., 2009). This general group is a random sample of evaluators at AEA who are not members of the Disabilities and Other Vulnerable Populations TIG or the International and Cross-Cultural and Evaluation TIG. These are evaluators who likely have a strong interest in evaluation practice, but not such as strong interest in working with disability or cross-cultural issues that they are members of those TIGs. This group represents the population of evaluators who may not be trained in inclusive practices.

The other two groups from AEA are census samples from the Disabilities and Other Vulnerable Populations (DOVP) TIG (N = 199, the disability group) and the International and Cross-Cultural Evaluations (ICCE) TIG (N = 870, the culture group). Members of the DOVP TIG are individuals who have both a strong interest in evaluation, as demonstrated by their membership in AEA, and a strong interest in conducting evaluations on programs for individuals with disabilities (IWD) or including IWD in evaluations. The TIG members may work with individuals with all types of disabilities, including physical disabilities. Therefore, the participants from this sample have a range of interest in and experience working with IWCD, but likely have more overall experience with inclusion than the general evaluation population. Because this study aimed to understand the extent to which IWCD are being included by a range of evaluators and promising practices for such inclusion, focusing on the DOVP TIG ensured that there would be some participants with relevant experience.

Both the DOVP and ICCE TIGs include members who have a particular interest in being culturally competent and inclusive. Evaluators in these TIGs likely have more experience making their evaluations accessible to individuals of multiple cultures and abilities than evaluators in the general group. Although not all members of the ICCE TIG may have experience with IWCD, the researcher was interested to see if their focus on cultural competence translated to increased inclusion for IWCD. Because these groups are smaller and a low response rate was expected for the online survey, the entire TIG populations were invited to participate. Students, however, were removed from all of the AEA groups because the study focused on experienced evaluators. It is likely that some experienced evaluators were excluded from the study because of this restriction. AEA participants were not recruited multiple times, and priority was given to the DOVP TIG followed by the ICCE TIG. Therefore, if an AEA member was in both TIGs, they were considered part of the DOVP TIG only and not included in the ICCE TIG sample. Participants in either the disability or culture groups were not included in the general group. After these restrictions, the final sample sizes were 862 for the general group, 155 for the disability group, and 655 for the culture group.

The fourth sample was a purposive sample of evaluators and directors who work at the 67 University Centers for Excellence in Developmental Disabilities (UCEDD). The UCEDDs are based in academic institutions around the country and some have evaluators who work on programs specifically designed for individuals with developmental disabilities. Although these centers primarily focus on development disabilities (i.e., cognitive disabilities that are diagnosed before age 22), they likely face similar challenges to those faced by evaluators working with individuals with other cognitive disabilities. Many of the directors of these centers have experience in program evaluation, as evaluation is often a required component of the grants they receive. Since not all directors were likely to be good candidates for this study, Dr. David Johnson, Director of the Institute of Community Integration, a UCEDD at the University of Minnesota and chair of the researcher’s doctoral committee, provided a list of the 31 most appropriate directors. The researcher also included all of the UCEDD evaluators listed in an online directory (N = 32). In the few cases where the evaluators were included in the AEA contact list, they were only included in the UCEDD sample since those surveys were the first to be distributed. These participants are experienced in working with IWCD and represent the higher end of inclusion experience. Although the researcher expected this sample size to be much smaller than the other groups, the hope was that this group would provide the expert perspective, particularly for the follow-up interviews.

Procedure

After drafting the survey and interview protocols, the researcher applied to the University of Minnesota's Institutional Review Board for exemption. The researcher received approval for exemption on January 3, 2014. An update do the sampling plan (increase in sample size) was approved on April 7th, 2014, after approval was received from AEA. Prior to piloting, the survey was posted on the online survey site Qualtrics. Two versions of the survey were set up, one for AEA members and one for the UCEDD members. The UCEDD survey had different introduction, acknowledging the participant's familiarity with individuals with disabilities, and modification of a few questions to avoid asking unnecessary information. At the end of the survey, all participants were asked if they would be willing to participate in an interview on the topic, and contact information was collected for those who indicated yes.

The AEA survey was conducted based on Dillman et al.'s (2009) three-stage strategy to maximize response rates for web-based surveys. First, potential participants were sent an introductory email that introduced the study and provided a link to the survey in late April. After 1 week, a second email was sent to non-responders reminding them to complete the survey. The survey link was again provided. A final email contact was made after another week to all non-responders emphasizing the deadline and importance of the study. According to Dillman et al., additional contacts do little to increase the response. The UCEDD sample was surveyed using the same procedure, except the emails were sent from Dr. David Johnson because potential participants would be more likely to participate if the request came from someone they knew. Only one reminder was sent to the UCEDD group to reduce any possible feelings of harassment from ICI. All contacts included personalized emails to the potential participants to increase trust with the participant and reduce the risk of being ignored or filtered by spam blockers. No incentives were provided to the survey participants.

A number of AEA participants responded to the researcher with either questions about the survey or to state that they were not interested in participating. Several participants asked for a definition of cognitive disabilities, suggesting they had not thoroughly read the email or survey introduction. Other email recipients replied that they do not work with IWCD and therefore were not the intended target, again showing they had not read the email. The researcher replied to all messages, answering those with questions and encouraging them to complete the survey. The respondents who stated they had no interest in the survey were immediately removed from the database so that they did not receive any follow-up reminders.

After the survey officially closed on May 14, 2014, the researcher downloaded the data from Qualtrics, stored the files on a secure server and prepared them for analysis in Excel and SPSS. The names were replaced with identification numbers to protect confidentiality. Those who volunteered to complete interviews had their data copied into a separate file for selection and to maintain the contact information they provided at the end of the survey. The identification information was later replaced with identification numbers for the interview analyses.

Phase 2: Interviews (Qualitative Method)

In Phase 2 of the study, interviews were conducted with evaluators to gain a deeper understanding of the considerations evaluators make when determining if and how to include IWCD and the challenges faced in the evaluation process when working with IWCD. The interviews provided the researcher with an opportunity to explore and possibly explain some of the survey findings. Including this qualitative approach in the research design allowed for richer data with which to construct new theories (Merriam, 2009). Interviews are beneficial because they allow the researcher to better understand the experiences and perspectives of the participants, providing further enlightenment around the issue of inclusion (Patton, 2002).

Protocol

One protocol was developed for the interviews with evaluators who have worked with IWCD (see Appendix B). A semi-structured interview format was used because it provided flexibility in the interview process, allowing the interviewer to probe for additional details and ensuring that participants have the opportunity to share their full opinions and experiences in the order they choose (Merriam, 2009). The interview protocol was initially developed based on themes from the literature. After the survey was conducted, the researcher reviewed the interview protocol for any necessary modification based on the survey results. The only modification that was made was the addition of a question on the relevance of the topic for general evaluators. The researcher then piloted the protocol with a colleague. After the pilot interview, the researcher asked several additional questions about the clarity and relevance of the questions. The researcher took notes during the pilot and identified several additional prompts for the questions and highlighted questions that may not be relevant to all interview participants, such as questions about the use of proxies.

Sample

The interview participants were selected using a purposive criterion sampling technique. Criterion sampling helps ensure information rich participants because the researcher can define the necessary inclusion criteria and select participants who meet them (Patton, 2002). The researcher selected the interview participants from the survey respondents. Out of the 538 surveys received from AEA members and UCEDD staff, 119 (22%) agreed to participate in an interview. The interviewees needed to have a fair amount of experience conducting evaluations with IWCD, particularly collecting data from this population. Therefore, the pool was restricted to respondents who stated they had collected data from IWCD at least 3 times. To ensure that the interviewees had some experience with evaluations and were not responding to the survey based more on research experience, participants who stated that they considered themselves primarily researchers were also excluded. In addition, the internationally based evaluators left in the sample pool were removed because of limited resources and the researcher’s desire to focus on practice within the United States. Another evaluator was removed because she was the only remaining candidate without a graduate degree. After the list was reduced using these criteria, the final list of 17 evaluators was contacted to participate in one-on-one telephone interviews, of which 12 agreed.

Procedure

After the interview protocol had been developed and participants were selected, the researcher sent an email to all potential participants that explained the study in detail again, asked for confirmation that they were still willing to participate, and requested possible days and times. The participants were advised that the interview would take approximately 30-60 minutes to complete, and that they would receive a $10 gift card to Target or Amazon.com as a thank you for their time. One additional email was sent to follow-up with participants who had not responded to the initial interview request. All interviews were conducted via telephone and were recorded with the participant’s permission. The researcher assured the interviewees that their names or identifying information would not be included in this dissertation or any other papers that are published as a result of this research.

Weiss (1998) suggests that telephone interviews are comparable to in-person interviews. Before each interview, the researcher explained the purpose of the study to the participants and verified consent. The interviewees were advised that they could stop the interview at any time and choose to not answer any questions. The researcher chose to conduct the interviews individually rather than in groups to allow the participants to share their experiences and opinions in confidence. Evaluators may feel less comfortable sharing their professional challenges in front of their peers. At the end of each interview, the researcher asked if the participants would like to receive a Target gift card mailed to them, or an Amazon.com card through email. Several participants declined the incentive, and those who accepted received them promptly. While the researcher was completing the interviews throughout June, 2014, the transcripts were sent to a transcriptionist who prepared verbatim transcriptions in preparation for analysis.

Analysis

The researcher conducted the analysis of the quantitative and qualitative data sets separately and sequentially. The researcher did preliminary quantitative analysis immediately after the data collection was completed so that the results could be used to inform the interview protocol development. The researcher completed the survey analysis before the qualitative analysis began. The researcher also analyzed the qualitative data from the surveys before coding the interviews. The quantitative and qualitative results will be compared in Chapter 5.

Quantitative Analysis

The researcher analyzed the survey data using the statistical software SPSS. Although the three AEA samples together provide a greater understanding of current evaluative thinking and practice, each sample comes from a unique purposive sample and was therefore not aggregated. Instead, the researcher analyzed each dataset independently, and the groups were compared statistically using Chi-square when appropriate and when no more than 20% of the cells had an expected count less than 5, as is a condition for such analysis (Coolican, 2004; Utts & Heckard, 2006). The type of statistical analyses appropriate to the dataset was limited due to the fact that part of the data is from census samples and because the all of the survey items are nominal or ordinal (Nardi, 2006). The researcher consulted with The Office of Research Consultation and Services at the University of Minnesota to confirm the analyses used were appropriate for these data. The analysis is primarily descriptive and includes the total frequencies for each variable and cross-tabulations. To examine bivariate data, the researcher produced cross-tables and calculated Chi-squares, which is an appropriate statistical test to use when examining the association between nominal and ordinal data (Nardi, 2006). Overall, the descriptive survey results provide a preliminary exploration of inclusion of IWCD in program evaluations. While there are numerous ways to compare the many variables in the survey, the researcher primarily focused on comparing the three AEA groups as well as on how some variables around the participants' experiences correlated to others. The quantitative analysis primarily answers research question 1, providing details about the perceived quality, type and level of participation of IWCD in evaluations. The survey results partially answer question 2, as the data reveal if evaluators consider including IWCD. The UCEDD final sample size was 16, and due to the small sample, size those results were not included in the quantitative analysis. Instead those results were used to identify interview participants, and the qualitative portions of the surveys were combined with the AEA responses.

Qualitative Analysis

The researcher completed the analysis of the interview data using the qualitative analysis software QDA Miner Lite. The software is a free version of QDA Miner that allows for basic coding of text documents and was satisfactory for this project. The researcher began the coding process by reading all of the interview transcripts to re-familiarize herself with the content. The researcher initially coded the interviews based on the question themes. For example, all responses to the question about methods used with IWCD were coded together. The researcher then further coded them inductively to group common answers. Depending on the number and length of responses for each question, some of the inductive coding was done intuitively as the researcher wrote up the results. The researcher then selected quotations that highlighted each theme. The researcher used the same process for the responses to the open-ended survey questions from the AEA and UCEDD participants.

Limitations

As with any study, there are several limitations to this research design that may influence the validity of the results and how they should be interpreted. As Dillman et al. (2009) explain, common errors when conducting surveys include coverage error, sampling error, nonresponse error, and measurement error. All of these errors are relevant in this study. Coverage error occurs when not all members of a population have a chance to be selected as a participant. The AEA random sample of general evaluators excluded those who had previously requested that the AEA not include them in research requests. This group of AEA members may have differed from other members. Sampling error is also relevant for the random sample of general evaluators. Based on an estimated AEA population of 6100 (without student members) and a sample size of 259, the calculated margin of error is 6%, with a confidence level of 95%, meaning that in 95% of cases the results will be accurate within 6% (Dillman et al., 2009).

Perhaps the biggest source of error in this study is nonresponse error. With a response rate of around 30% across the different survey groups, a large proportion of potential participants chose not to complete the survey. There are many possible reasons that participants did not complete the survey, and some of those reasons will have more influence on the results than others. Some evaluators may simply not check the email account they use for AEA regularly. Others may dislike completing online surveys. A number of participants emailed the researcher and stated they did not feel they were the target population for the survey. It is likely that other evaluators had the same thought, but did not email the researcher. These individuals can skew the survey results since they may be the evaluators with the least experience or interest in working with IWCD. The individuals who did respond to the survey may be advocates wanting to help further the cause of inclusion, or they may have been eager to help out a dissertation student. These nonresponse or response biases impacted interview participation as well since all interview participants had to have completed the entire survey (the question about participating in the interviews was at the end of the questionnaire). Several of the participants who were contacted for the interview portion of the study did not respond, and again this group may have had some important differences from those who did. They may have felt less qualified to speak in depth on the subject.

Despite piloting, both the survey questionnaire and the interview protocol may include items that were not clear to all participants, resulting in measurement error. As described by Dillman et al. (2009), “measurement error is often the result of poor question wording or design and other aspects of questionnaire construction” (p. 18). During the interviews the researcher was able to clarify any confusing questions, but that was not possible during the survey. The survey relied on participants reading the introduction where cognitive disabilities were defined, and some respondents may have skipped that section. A few participants left comments that they disliked how the questionnaire was constructed or felt the questions contained too much jargon or were too general. All of these issues may have resulted in inaccurate responses from the participants.

Another limitation to this study is the fact that the population parameters are limited to members of AEA and UCEDD staff. There are many evaluators in the country who are not associated with either institution, and the extent to which the results can be generalized to them is limited. Likewise, although there were some international participants in the survey sample, the majority of survey participants and all of the interviewees were based in the United States. These results are therefore not generalizable to other countries that have different cultures and policies related to disability and evaluation.

Chapter 4: Research Results

Chapter four includes quantitative and qualitative findings from the analysis of both stages of the mixed method study. The results are explored in two sections. The first section of this chapter presents the results from the closed-ended and open-ended responses to the survey questions that were distributed to members of the American Evaluation Association (AEA). The second section presents the findings from the interviews conducted with evaluators who have considerable experience with including individuals with cognitive disabilities in their evaluations.

Survey Results

As described in Chapter 3, the survey was distributed to three groups of evaluators who are members of AEA. The survey results are divided into four sections: response rates, background, experience with IWCD, and open-ended responses. Each group's survey results are presented separately because the population of evaluators without a strong focus on disability or culture are likely different from those with such a focus. In some situations it is interesting to compare the groups, although for many variables each groups' results are interesting in of themselves.

The total response rate for the surveyed members at AEA is 31%, with a response rate for the disability group reaching 41% and the rates for the general and culture groups at around 30% (see Table 2). Although the number of responses received varied by question, all surveys that were more than half complete were included in the analysis. The response rates for the UCEDD directors and evaluators were somewhat lower, and, since these groups have small sample sizes, their responses are only included in the open-ended question analyses. Their other responses were used to identify potential interview participants.

Table 2

Survey Response Rates by Group

Group	Number contacted	Number responded	Response rate
AEA General Members (General)	862	259	30%
AEA Disabilities and Other Vulnerable Populations TIG Members (Disability)	155	63	41%
AEA International and Cross-Cultural Evaluation TIG Members (Culture)	655	200	31%
Total AEA	1672	522	31%
UCEDD Directors	31	9	29%
UCEDD Evaluators	32	7	22%
Total UCEDD	63	16	25%

Note. These response rates only include participants who completed at least half of the survey.

Response rates for the open-ended questions were high. The survey included three questions that allowed participants to provide their opinion and experiences around working with IWCD in evaluation settings. The majority of participants responded to the first two questions that asked about the benefits and challenges of including IWCD in evaluations (see Table 3). Not surprisingly, the disability group had a higher response rate to these questions than the general and culture groups.

Table 3

Response Rates for Open-Ended Survey Questions by Group

Group	Benefits question (*n* = 387)	Challenges question (*n* = 394)	Additional comments (*n* = 125)
General	72.2% (187)	72.2% (187)	22.4% (58)
Disability	90.5% (57)	90.5% (57)	34.9% (22)
Culture	71.5% (143)	75.0% (150)	22.5% (45)

Group Descriptions

The questionnaire asked several questions about the participants' demographics and background as evaluators. These questions were used to examine differences between and among the groups and as potential factors correlating with the inclusion of IWCD in evaluations. As shown in Table 4, over two-thirds of the participants were female, and the majority had doctoral degrees. No participants had achieved less than a Bachelor's degree. Most participants classified themselves as either primarily evaluators or as equally researchers and evaluators. The majority of participants had at least 5 years of evaluation experience and at least one third of the participants in each group had 15 or more years of experience. Pearson's Chi-Square analysis showed no statistically significant differences between the three groups on these variables. Almost all of the members of the general and culture groups had never been a member of the Disabilities and Other Vulnerable Populations TIG. Twenty of the participants from the disability group were not aware that they were currently in the TIG. These participants are likely not currently active in the TIG, but had at some point made the decision to join.

Table 4

Cross-Tabulation Frequencies of AEA Survey Respondents' Demographic Characteristic by Group

Demographic	General	Disability	Culture
Gender[a]			
Female	68.7% (*n* = 169)	70.5% (*n* = 43)	68.7% (*n* = 136)
Male	29.7% (*n* = 73)	29.5% (*n* = 18)	30.8% (*n* = 61)
Education			
Bachelor's	4.1% (*n* = 10)	1.6% (*n* = 1)	1.5% (*n* = 3)
Master's	39.8% (*n* = 97)	30.6% (*n* = 19)	42.4% (*n* = 84)
Doctorate	56.1% (*n* = 137)	67.7% (*n* = 42)	56.1% (*n* = 111)
Self-Classification			
Primarily an evaluator	33.9% (*n* = 83)	35.5% (*n* = 22)	41.6% (*n* = 82)
Primarily a researcher	12.7% (*n* = 31)	8.1% (*n* = 5)	10.2% (*n* = 20)
Equally a researcher and evaluator	34.3% (*n* = 84)	41.9% (*n* = 26)	29.4% (*n* = 58)
Other	19.2% (*n* = 47)	14.5% (*n* = 9)	18.8% (*n* = 37)
Years experience in evaluation			
0 to 4 years	24.6% (*n* = 60)	9.7% (*n* = 6)	21.2% (*n* = 42)
5 to 9 years	28.7% (*n* = 70)	22.6% (*n* = 14)	23.2% (*n = 46)*
10 to 14 years	13.5% (*n* = 33)	21.0% (*n* = 13)	16.7% (*n* = 33)
15 or more years	33.2% (*n* = 81)	46.8% (*n* = 29)	38.9% (*n* = 77)
Disability TIG membership			
Current	2.5% (*n* = 6)	67.6% (*n* = 42)	3.0% (*n* = 6)
Formerly	0.8% (*n* = 2)	8.1% (*n* = 5)	1.0% (*n* = 2)
Never	94.7% (*n* = 230)	17.7% (*n* = 11)	94.4% (*n* = 187)
Don't know	2.1% (*n* = 5)	6.5% (*n* = 4)	1.5% (*n* = 3)

[a] Participants were also given the options of "Other" and "Prefer not to say"

The questionnaire included several questions about the type of evaluation work the participants have done recently (Table 5). The majority of participants across all groups have done work in the education and social services fields in the last 5 years, although the culture group had fewer evaluators in the education field. Just fewer than half of the participants in each group had conducted evaluations in the health care field in the last 5 years. Significantly more participants in the disability and culture groups have recently worked in the nonprofit area ($\chi2$ (2) =6.7, n=489, p<.05).

Table 5

Cross-Tabulation Frequencies of AEA Survey Respondents' Areas of Practice by Group

	General		Disability		Culture	
Variable	Yes	No	Yes	No	Yes	No
Types of evaluation practiced over last 5 years						
Education	79.8% (165)	29.2% (68)	73.8% (45)	26.2% (16)	61.1% (116)	38.9% (74)
Nonprofit*	69.5% (162)	30.5% (71)	75.8% (47)	24.2 (15)	80.4% (156)	19.6% (38)
Social services (government run)	53.3% (120)	46.7% (105)	65.6% (40)	34.4% (21)	50.8% (95)	49.2% (92)
Health care	45.5% (105)	54.5% (126)	45.0% (27)	55.0% (33)	43.2% (82)	56.8% (267)
Currently practicing in settings						
Post-secondary academic institution*	43.8% (102)	56.2% (131)	43.1% (25)	56.9% (33)	27.7% (51)	72.3% (133)
PreK-12 education institution*	16.1% (35)	83.9% (182)	23.2% (13)	76.8% (43)	9.4% (17)	90.6% (163)
Nonacademic government agency*	33.5% (74)	66.5% (147)	16.7% (9)	83.3% (45)	35.1% (65)	64.9% (120)
Nonacademic nonprofit organization	38.5% (85)	61.5% (136)	36.2% (21)	63.8% (37)	44.9% (83)	55.1% (102)
For-profit organization	22.0% (48)	78.0% (170)	20.0% (11)	80.0% (44)	24.9% (45)	75.1% (136)
As an independent contractor	42.7% (97)	57.3% (130)	41.8% (23)	58.2% (32)	51.9% (98)	48.1% (91)

*p < .05, ** p < .005, *** P < .001

The culture group had fewer participants currently working at post-secondary academic institutions ($\chi2$ (2) =12.2, n=475, p<.05). The disability group had the most participants working at preK-12 education institutions, followed by the general group (χ^2 (2) =7.7, n=453, p<.05). The disability group had fewer evaluators working in nonacademic government agencies than the other groups ($\chi2$ (2) =6.9, n=460, p<.05). There were also significant differences between the groups in the number of participants working in nonacademic non-profit organizations, for-profit organization or as independent contractors.

Experience with IWCD

The questionnaire asked participants several questions about the extent to which they have worked in the disability field and included IWCDs in evaluations. As expected, almost all (98.4%) of the disability group has worked in the disability field in some way (see Table 6). About one third of the general and culture groups had experience working in the disability field ($\chi2$ (2) =89.3, n=521, p<.001). This question was not focused specifically on IWCD, but the researcher theorized that those with a focus on disability would be more aware of issues with cognitive disabilities as well. As predicted, members of the general and culture groups who had worked in the disability field were significantly more likely to have made accommodations in an evaluation for IWCD (χ^2 (1) =20.6, n=255, p<.001, χ^2 (1) =23.3, n=195, p<.001, respectively).

One question asked respondents to specify how they have worked in the disability field. Almost all participants who answered "Yes" to having worked in the field shared details. Many of the respondents mentioned that they are or have conducted research or evaluation projects with individuals with disabilities. In addition, participants mentioned having worked in special education classrooms or school districts or in clinical settings such as day centers and long-term care facilities either as a supervisor, administrative staff, or by providing direct services. Several participants had worked in public policy positions and in an advocacy capacity. Other participants mentioned working with family members who have disabilities. Overall and perhaps not surprisingly the evaluators in the disability group had significantly more experience in evaluating programs for IWCD ($\chi 2$ (6) =110.4, n=522, p<.001) and have been more likely to make accommodations for IWCD than individuals in the general and culture groups ($\chi 2$ (2) =38.0, n=512, p<.001).

Table 6

Cross-Tabulation Frequencies of AEA Survey Respondents' Experience working with Individuals with Disabilities Generally and in Evaluations by Group

Item	General	Disability	Culture
Worked in disability field in any way***			
Yes	38.6% (100)	98.4% (62)	32.7% (65)
No	61.4% (159)	1.6% (1)	67.3% (134)
Number of evaluations worked on for programs primarily serving IWCD***			
None	79.2% (205)	28.6% (18)	83.5% (167)
1 to 2	12.4% (32)	28.6% (18)	10.0% (20)
3 to 4	5.4% (14)	9.5% (6)	3.0% (6)
5 or more	3.1% (8)	33.3% (21)	3.5% (7)
Ever made accommodations for IWCD in an evaluation***			
No	67.8% (173)	31.1% (19)	73.5% (144)
Yes	32.2% (82)	68.9% (42)	26.5% (52)

*p < .05, ** p < .005, *** P < .001

The questionnaire asked participants to state to what extent and in what ways that they have included IWCD in evaluations, if any (Table 7). When asked about the inclusion of IWCD in previously compiled public data sets, the culture group had the least experience, with 83.2% stating they had never purposely included IWCD in this way, followed by the general group with 73.0%. The majority of the disability group had included IWCD in this way at least once (60.7%). The differences between these groups were statistically significant at χ^2 (6) =50.2, n=508, p<.001.

Table 7

Cross-Tabulation Frequencies of AEA Survey Respondents' Inclusion of IWCD in Various Ways by Group

Variable	Never	1 to 2 times	3 to 4 times	5 or more times	Total	χ2
Included IWCD in previously compiled public data sets						
General	73.0% (187)	13.7% (35)	3.5% (9)	9.8% (25)	100% (256)	
Disability	39.3% (24)	24.6% (15)	6.8% (4)	29.5% (18)	100% (61)	50.2***
Culture	83.2 (159)	9.9% (19)	2.1% (4)	4.7% (9)	100% (191)	
Included IWCD in data someone else collected for the evaluation						
General	70.4% (178)	17.0% (43)	5.1% (13)	7.5% (19)	100% (253)	
Disability	31.1% (19)	39.3% (24)	3.3% (2)	26.2% (16)	100% (61)	62.4***
Culture	79.7% (153)	11.5% (22)	4.2% (8)	4.7% (9)	100% (192)	
Collected data directly from IWCD						
General	68.2%(173)	22.7% (58)	4.7% (12)	4.3% (11)	100% (255)	
Disability	32.3% (20)	29.0% (18)	6.5% (4)	32.3% (20)	100% (62)	79.6***
Culture	75.5%(148)	16.3% (32)	5.1% (10)	3.1% (6)	100% (196)	
Included IWCD as evaluation team consultant						
General	86.3% (220)	9.0% (23)	2.0% (5)	2.7% (7)	100% (255)	
Disability	59.0% (36)	21.3% (13)	9.8% (6)	9.8% (6)	100% (61)	37.2***
Culture	89.1% (171)	7.8% (15)	1.6% (3)	1.6% (3)	100% (192)	
IWCD worked as full member of evaluation team						
General	88.2% (224)	7.5% (19)	2.0% (5)	2.4% (6)	100% (254)	
Disability	76.7% (46)	10.0% (6)	6.7% (4)	6.7% (4)	100% (60)	NA[a]
Culture	93.3% (181)	3.1% (6)	2.1% (4)	1.5% (3)	100% (194)	
IWCD worked as the Principal Investigator of the evaluation						
General	93.7% (239)	3.5% (9)	0.8% (2)	2.0% (5)	100% (255)	
Disability	89.8% (53)	0.0% (0)	3.4% (2)	6.8% (4)	100% (59)	NA[a]
Culture	94.7% (189)	1.5% (3)	0.5% (1)	0.5% (1)	100% (194	

[a] Significance not available due to low expected counts in more than 20% of cells. *p < .05, ** p < .005, *** P < .001

As shown in Table 7, similar results were seen for including IWCD as individuals from whom someone else collected data for the evaluation (χ^2 (6)=62.4, n=506, p<.001) and as participants from whom the respondent collected data directly (χ^2 (6)=79.6, n=513, p<.001). When asked about using IWCD as consultants for the evaluation team, the majority in all three groups had never done so, although more of the disability group had experience in this area than the other groups (χ^2 (6)=37.2, n=508, p<.001). Very few participants from any group had experience including IWCD as a member of the evaluation or as the principal investigator of an evaluation, although in both cases the disability group had slightly more experience than either general or culture. Chi-square analysis for these variables could not be calculated due to small cell counts. In all cases, the culture group had slightly less experience including IWCD than did the general group.

In addition to asking respondents their amount of experience including IWCD, the questionnaire asked them to share their opinions on inclusion by stating whether they agree or disagree with several statements (Table 8). The majority of disability participants agreed or strongly agreed that most of the programs they evaluate serve some IWCD. Conversely, the majority of culture and general participants disagreed with this statement (χ^2 (6) =61.9, n=517, p<.001). The majority of the disability participants felt they could generally determine if there are IWCDs in the programs they evaluate, while the majority of general and culture participants did not (χ^2 (6)=48.9, n=512, p<.001). These findings suggest that even though participants in the general and cultural groups may not believe the programs they evaluate include IWCD, they may not be able to tell if that is the case or not. Similarly, while most of the disability participants agreed that they

Table 8

Cross-Tabulation Frequencies of the Extent to Which AEA Survey Respondents' Agree or Disagree with Statements by Group

Variable	Strongly agree	Agree	Disagree	Strongly disagree	Total	χ2
Most programs I evaluate serve some IWCD						
General	11.0% (28)	33.7% (86)	29.0% (74)	26.3% (67)	100% (255)	
Disability	42.9% (27)	25.4% (16)	25.4% (16)	6.3% (4)	100% (63)	61.9***
Culture	8.0% (16)	26.1% (52)	39.7% (79)	26.1% (52)	100% (199)	
I can usually determine if there are IWCD in programs that I evaluate						
General	7.5% (19)	34.8% (88)	44.7% (113)	13.0% (33)	100% (253)	
Disability	27.0% (17)	47.6% (30)	17.5% (11)	7.9% (5)	100% (63)	48.9***
Culture	4.6% (9)	30.6% (60)	43.9% (86)	20.9% (41)	100% (196)	
I know ways to modify data collection methods for IWCD						
General	6.7% (17)	31.1% (79)	39.8% (101)	22.4% (57)	100% (254)	
Disability	25.8% (16)	45.2% (28)	27.4% (17)	1.6% (1)	100% (62)	52.4***
Culture	3.6% (7)	28.4% (56)	39.6% (78)	28.4% (56)	100% (197)	
I feel comfortable collecting data from IWCD						
General	9.2% (23)	37.5% (94)	40.2% (101)	13.1% (33)	100% (251)	
Disability	35.0% (21)	40.0% (24)	25.0% (15)	0.0% (0)	100% (60)	48.2***
Culture	7.3% (14)	42.4% (81)	32.5% (62)	17.8% (34)	100% (191)	
Evaluators should always make the necessary accommodations for an IWCD to participate						
General	36.9% (92)	49.8% (124)	11.2% (28)	2.0% (5)	100% (249)	
Disability	58.7% (37)	39.7% (25)	1.6% (1)	0.0% (0)	100% (63)	NA[a]
Culture	32.6% (62)	47.9% (91)	16.8% (32)	2.6% (5)	100% (190)	

[a] Significance not available due to low expected counts in more than 20% of cells *p < .05, ** p < .005, *** P < .001

know how to modify data collection methods for IWCD, the majority of the general and culture groups disagreed with the statement (χ^2 (6) =52.4, n=513, p<.001). About half of the general and culture groups agreed that they felt comfortable collecting data from IWCD, compared to 75% of the disability group (χ^2 (6) =48.2, n=502, p<.001). The vast majority of evaluators agreed or strongly agreed that evaluators should always make the necessary accommodations for IWCD to participate, with 98.4% of disability participants agreeing, followed by 86.7% of general participants and 80.5% of the culture participants (significance not calculated due to low cell counts).

Evaluators who stated they did not have experience including IWCD in evaluations, as participants from whom they or someone else collected data for the evaluation, as consultants, or as full members of the evaluation, were asked several questions about whether or not they have ever considered such inclusion. Except for disability respondents who considered IWCD as participants, the majority of responders for each group answered no. The general and culture group had very similar percentages for each category, with about one-fifth considering inclusion as participants, and very few considering inclusion in the other aspects. While all of these group differences were statistically significant using Chi-square, the cell counts for the disability group were very low for these variables since most of those participants had some experience with inclusion.

The survey asked participants how often they practice different types of evaluation, including Culturally Competent, Transformative, Participatory, Formative, and Summative, to determine if participants who focus more on one type of evaluation were more likely to have made accommodations for IWCD. For the general participants, those who have made accommodations were significantly more likely to say they frequently (43.8%) or always (39.2%) conduct culturally competent evaluations. None of the other comparisons between evaluation type and experience with accommodations were significant for any group.

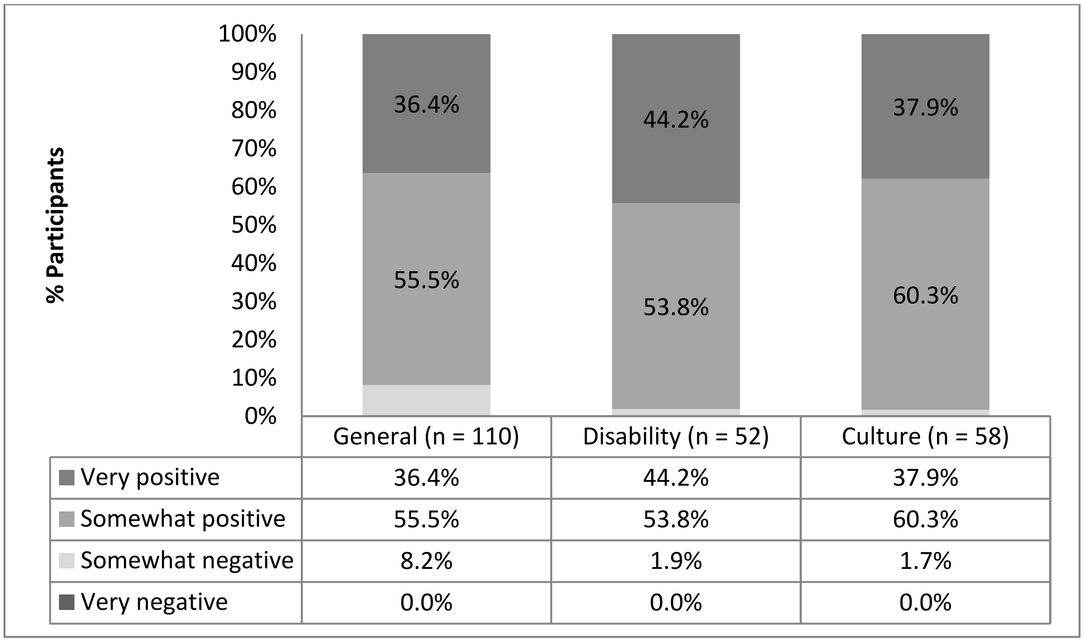
Table 9

Cross-Tabulation Frequencies of Whether AEA Survey Respondents Who Have Not Collected Data From IWCD but Have Considered Their Inclusion in Various Ways by Group

Variable	Yes	No	Total	χ2
As participants				
General	18.2% (24)	81.8% (108)	100% (132)	
Disability	55.6% (5)	44.4% (4)	100% (9)	7.132*
Culture	21.4% (28)	78.6% (103)	100% (131)	
As consultants				
General	3.0% (4)	97.0% (128)	100% (132)	
Disability	33.0% (3)	66.7% (6)	100% (9)	20.577***
Culture	3.1% (4)	96.9% (127)	100% (131)	
As a member of the evaluation team				
General	5.3% (7)	94.7% (125)	100% (132)	
Disability	22.2% (2)	77.8% (7)	100% (9)	8.417*
Culture	2.3% (3)	97.7% (128)	100% (131)	

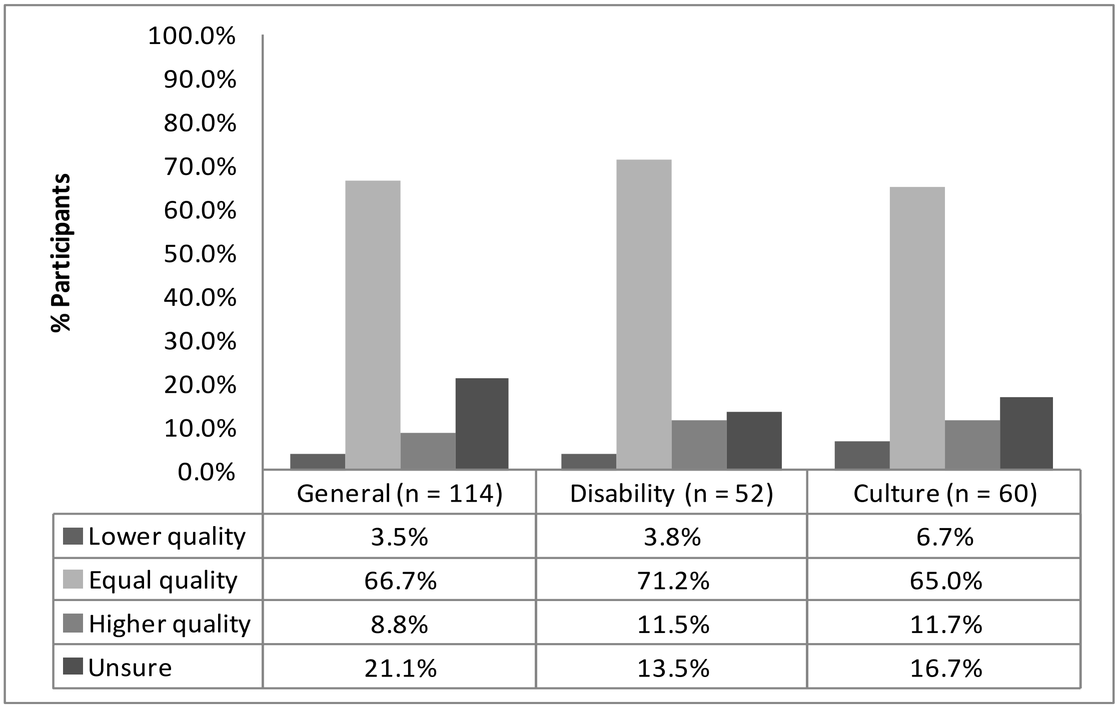
*p < .05, ** p < .005, *** P < .001

Participants who included IWCD in their evaluations in any way answered a series of questions about their experiences. As shown in Figure 3, almost all participants in each group had a very positive or somewhat positive experience with those evaluations (*n* = 220). No participants reported having a very negative experience. About two-thirds of the participants felt that the evaluations they conducted with IWCD were of equal quality to their other evaluations (Figure 4, *n* = 226). Each group also had participants who felt the evaluations they conducted with IWCD were higher and lower quality than the evaluations they conducted without IWCD, and 13.5% to 21.1% were unsure if there was a difference in quality.



	General (n = 110)	Disability (n = 52)	Culture (n = 58)
■ Very positive	36.4%	44.2%	37.9%
■ Somewhat positive	55.5%	53.8%	60.3%
■ Somewhat negative	8.2%	1.9%	1.7%
■ Very negative	0.0%	0.0%	0.0%

Figure 3. Participants’ experience including IWCD in their evaluations.



	General (n = 114)	Disability (n = 52)	Culture (n = 60)
■ Lower quality	3.5%	3.8%	6.7%
■ Equal quality	66.7%	71.2%	65.0%
■ Higher quality	8.8%	11.5%	11.7%
■ Unsure	21.1%	13.5%	16.7%

Figure 4. Participants' views on the quality of the evaluations in which they included IWCD.

When asked about the types of methods used with IWCD, the most common form of data collection across all groups was individual interviews (70.4 – 78.0%), followed by questionnaires and observations (Figure 5). Fewer of the culture group used psychometric testing than disability and general, likely because of the reduced number of participants in the K-12 Education Field.

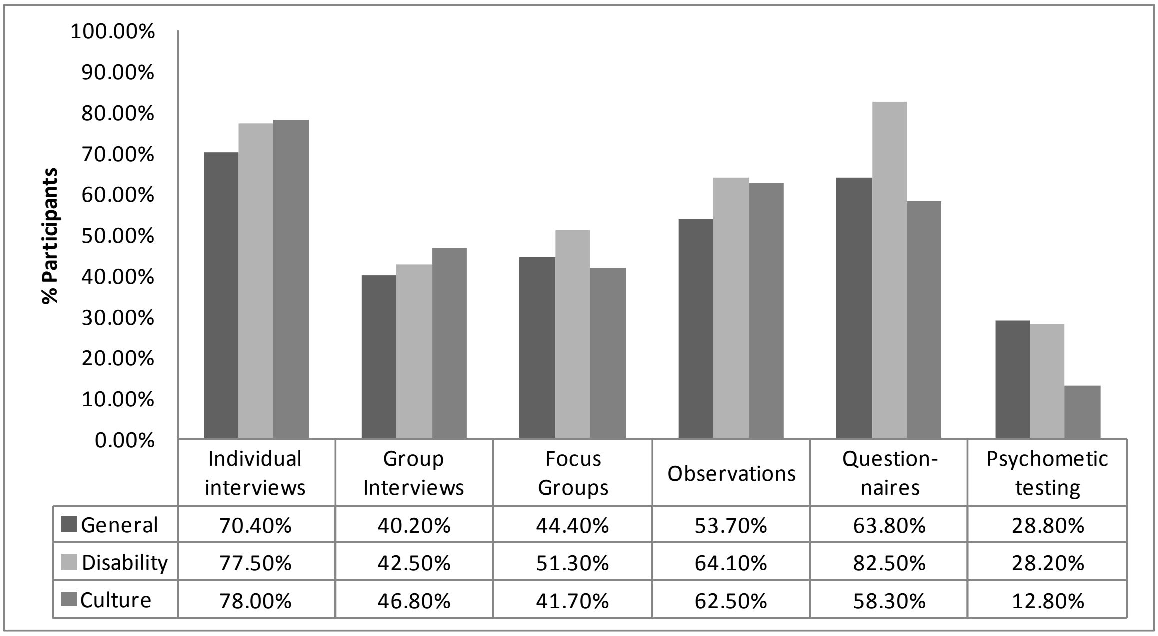


Figure 5. Percent of participants who used evaluation data collection methods with IWCD.

Open-Response Questions

In addition to specifying in what way or ways the participants have worked in the disability field, the survey included three open-ended questions to which participants were asked to respond. This section summarizes the comments by presenting common themes among them and provides select examples to demonstrate those themes. The themes that appeared in these responses had little variation between the participant groups and are therefore presented in aggregate. In addition to the three AEA groups that were surveyed, the responses from the UCEDD participants are included with these results, as their responses touched on the same themes.

Table 10

Themes and Example Quotations of the Potential Benefits of Including IWCD in Program Evaluations

Theme	Representative example quotations
Equal rights	"If they are a significant portion of the beneficiary, they should be treated like any other group and be included. I am not convinced that they need to be included as consultants or member of the evaluation team except maybe in special situations that may arise." "If they are part of the target population of a given program or service, they should be included in evaluations of the program/service (assuming some judgment about the cost effectiveness/risk of not including this part of the population has been made)." "If they comprise [a] non-trivial portion of your client's target population, it would be inappropriate and unethical not to include them in most phases of the evaluation." "It contributes to a democratic society."
General betterment	"An important segment of any population. Including individuals with cognitive disabilities ensures that you make the study simple and easy to understand. Everyone benefits from this." "If the program serves people with cognitive disabilities then the evaluation must include those individuals. As with any participatory approach, the benefits of inclusion far outweigh the inherent difficulties."
Unique perspective	"Their perspective is often unique and indicate areas where programs can adapt their interventions to ensure access to all." "As evaluation participants, people with cognitive disabilities can provide rich information about their experiences with the program or project I'm evaluating. As evaluation consultants, people with cognitive disabilities can provide important insights into how others with cognitive disabilities will experience the project I'm evaluating." "Individuals with disabilities offer unique and important perspectives. It is part of being culturally responsive and is obviously even more critical if the focus population of an evaluation includes or is primarily comprised of individuals with disabilities." "Each person with a cognitive disability has a wealth of experience and knowledge, some of which is not common to people who do not have

Themes and Example Quotations of the Potential Benefits of Including IWCD in Program Evaluations

Theme	Representative example quotations
	cognitive disabilities. They provide unique perspectives that otherwise would be absent.” “To better understand how the program is helping or hindering a marginalized group.”
Validity	“Just the sheer fact that there are lots of individuals with cognitive disabilities--often unseen--in any given stakeholder group means it's kind of a "fact of life" that we need to include individuals with cognitive disabilities in our evaluations to get a full picture of program impact.” “One purpose of evaluations is to hear the "voice" of individuals regarding the program or service that is being evaluated. To disregard the voice of individuals with cognitive disabilities potentially excludes an important piece of data.” “If the end result of an evaluation is to identify successes and obstacles to implementation and resulting outcomes, it is important to include all populations in the evaluation. If a program serves persons with disabilities, then a truly representative evaluation would include their experiences.” “The random selection of subjects is not jeopardized.” “Greater overall validity of evaluation data and findings.”

Benefits. The questionnaire asked participants what they feel are the benefits of including individuals with cognitive disabilities in evaluations. Many respondents referred to the importance of including the individual’s voice or perspective, both to more accurately evaluate the program and make representative recommendations and to be equitable and inclusive of all program participants. Some participants felt there would be little benefit in the type of programs they evaluate; others explained that whatever benefits there may be would depend on the specific evaluation. Participants also mentioned that as long as IWCD were part of the program, they should be included in the evaluation. Others felt that IWCD should make up a significant percent of the program population to warrant the additional effort and cost to include them. Overall, the comments around benefits of inclusion fell into 4 themes: Equal rights for IWCD; general betterment of evaluations, and thus society; the addition of a unique perspective or often excluded voice, and increased validity or accuracy of the evaluation results. Table 10 presents those themes along with select representative quotations.

Challenges. The questionnaire also asked participants to share what they feel are the challenges to including individuals with cognitive disabilities in evaluations. Although these questions could refer to inclusion as participants or evaluation team members, most participants focused on challenges in working with participants. Some participants felt that they were unable to respond to the question because they had never considered including IWCD. Others responded based on their actual experiences working with IWCD, and many theorized based on their general experience as evaluators. Many participants mentioned multiple challenges, so the sample quotations provided below each theme are listed under the primary topic mentioned.

Logistical challenges. Several of the topics participants mentioned in this section had to do with the practical and logistical obstacles to including IWCD in evaluation. Participants expressed concern over being able to identify IWCD in their programs, particularly if those programs did not specifically serve that population.

Table 11

Themes and Example Quotations of the Challenges of Including IWCD in Program Evaluations: Logistical Considerations

Theme	Representative example quotations
Multiple groups	“There's a lot of variability in this population labeled ‘cognitive disabilities’; involvement of some doesn't guarantee meaningful accommodations for all.” “Unsure how to be inclusive of persons with a wide range of individuals with cognitive disabilities.” “Current evaluation project is with an already very difficult to reach population... so expanding this project to ensure inclusion of individuals with cognitive disabilities is not feasible. In addition, some populations have highly protective attitudes towards individuals with cognitive disabilities and prevent those individuals from interacting with people outside their immediate families. Given this, is can be very hard to reach such individuals in some contexts.”
Identification	“It's hard to have a sense of the breadth of cognitive disabilities out there that I should take into account. I don't feel well-versed in that at all--so it starts at that fundamental awareness level. My awareness stops at “I know individuals with cognitive disabilities are out there, and present in every evaluation I do, but...’ ” “Identification, as many individuals do not feel comfortable disclosing disability.” “Recognizing the individuals if they are part of a study not focused on cognitive disabilities, having tools and knowledge of how to accommodate.”
Time and money	“Unless a program is specifically designed for individuals with cognitive disabilities, resource constraints are likely to be an important factor limiting support for including these individuals in evaluations not targeted specifically for them.” “Accessibility and accommodations are expensive and time consuming; many professionals are willing to write off this group of participants as too difficult to include; it takes time to develop the relationships that will result in good data; there are many more steps needed in doing instrument development and piloting; etc.” “Evaluator capacity, time, money.”

Themes and Example Quotations of the Challenges of Including IWCD in Program Evaluations: Logistical Considerations

Theme	Representative example quotations
	“Additional time to develop materials/questions/processes that are appropriate, and time to analyze resulting data that might be in a different form. Expense in ensuring access to people with CD.” “The logistics and cost associated with having different collection protocols, and data collectors, for different types of cognitive disabilities.”
Small group	“Drawing on a recent example from my own work... the extremely small proportion of persons served by a program being evaluated who had cognitive disabilities made it difficult to justify the added cost of recruiting a comparison group that would have similar cognitive disabilities. Since the ultimate goal was to draw from a general population of participants, it made the most financial sense to concentrate on the participants who were not previously categorized/identified as persons with disabilities (that said, there may very well be persons with cognitive disabilities in our study that we are not aware of). In addition, some of the people "on the ground" expressed concerns that administering the same surveys with their constituents could be very time-consuming and take away from the benefits of participation in the program itself.” “In my experience, those with cognitive disabilities are a very small subgroup/proportion of the population being studied (if it is even known), and typically not the focus of the funder/organization. The challenge would be determining if the extra cost and resources required to engage them would be worth the extra information gathered for evaluation of the overall program.” “Unless a study is specifically targeting this population, I do not think that evaluators typically think about this population and thus, budgets and data collection techniques are rarely adapted for inclusion of this group.”

Further, many IWCD and their families do not disclose a disability even if the individual would be better served with accommodations. Others mentioned the challenge of providing accommodations for individuals with a wide range in type and degree of disabilities who may be present in a target population. Several participants also felt that they are already trying to cater to multiple groups, such as multiple languages, or education levels, and do not have the capacity to focus on disability as well.

Many responses concerned the additional time and funding that is required when making accommodations for this population. A few people mentioned the transportation needs of IWCD as an obstacle. Several participants questioned whether or not their funding agencies would be willing to support such an endeavor.

Technical and Social Skills. The majority of respondents mentioned the challenge of adjusting data collection tools and processes to accommodate IWCD and needing the training to do so (Table 12). Respondents mentioned the importance of knowing how to work with this population. Some respondents felt they would need to develop the skill to effectively communicate with IWCD, to feel comfortable working with this population, and for the individuals to feel comfortable working with them.

In addition to challenges in data collection, participants discussed challenges with data analysis and maintaining validity in the study overall. Some participants felt that the small number of IWCD in a program would present analytical challenges, particularly with quantitative data. Others felt it would be difficult to know if they responses provided were accurate or if they were being interpreted correctly.

Table 12

Themes and Example Quotations of the Challenges of Including IWCD in Program Evaluations: Methodological and Social Themes

Theme	Representative example quotations
Methodological challenges	“Finding data collection methods that "work" for them. Language has to be kept simple and establishing rapport can be difficult because some may find us intimidating.” “We want to capture their experience yet our tools do not always align to their abilities. We need to find new strategies that work with their strengths in communicating their experiences.” “There is an obvious need for education about how to meaningfully include folks with disabilities - participation is not, for example, just ensuring representation through participation at a committee or meeting which operates in a typical fashion. Accommodations should be made to ensure that folks can feel their participation has actually been meaningful. Info[rmation] is also needed to ensure that data collections tools are inclusive and/or can be adapted.” “The extent of the cognitive challenge and the limits of evaluator creativity.”
Technical training needs	“Lack of training in how to make accommodations and Institutional Review Boards for those of us who work at universities.” “Creating multiple evaluation or survey tools for the able-bodied/minded and those with cognitive disabilities. Often, evaluators don't have the know-how or the funding to create those tools.” “Lacking the expertise in knowing how to do this appropriately.”
Skills/comfort working with IWCD	“The evaluator(s) need to be sensitive and patient while at the same time remaining objective.” “Inclusion requires evaluators to be aware of adaptive needs, or accommodations for unexpected events that may not be present in a general population, and to build this into the design, without making it "a big deal" or singling out any individual(s). It is a type of cultural humility, in my opinion.” “Their comfort and gaining their trust as an outsider.” “Identifying triggers to aid memory, patience helping them to give response.”

Themes and Example Quotations of the Challenges of Including IWCD in Program Evaluations: Methodological and Social Themes

Theme	Representative example quotations
	“I'm not trained to deal with individuals with cognitive disabilities, and I would like to make sure I treat them appropriately.”
Maintaining validity	“Overuse of their responses to identify needs and next steps.” “Triangulation is difficult because the information they provide may not be able to be verified elsewhere. Additionally, it is difficult to understand their narrative of where and how complex processes are inadequate or fail to meet their needs.” “Depends on the level of disability. I think it may affect the types of questions and response sets asked, causing some of the data to no longer be comparable. Also, it might affect the types of indicators that can be used in the study. I think there is also the ethical challenge of assent and consent. I am not familiar with it, so I do not know what is considered standard procedure.” “Knowing how to approach evaluation with the various types of disabilities. Knowing how to interpret the data -- for example, are responses going to vary according to the time of day the evaluation was done? Is someone influenced by another respondent?” “Modifying tools without compromising standardization of responses.”

Ethical Considerations. Other common challenges that participants mentioned included making sure the participants were really providing informed consent and needing to modify the consent process. Such modification may be difficult when needing approval from an institutional review board (IRB). Some participants noted that IWCD may be considered a special population by the IRB and would therefore require a more intensive, and thus lengthier, review process. Participants also mentioned the challenge of being able to identify when a proxy needs to be used, or when to encourage the families to allow the individual to respond directly.

Table 13

Themes and Example Quotations of the Challenges of Including IWCD in Program Evaluations: Ethical Considerations

Theme	Representative example quotations
IRB and consent	"Ensuring that they fully understand the ethical implications of participation and can provide informed consent. For me, this is really important as I want to ensure that individuals with cognitive disabilities are not taken advantage of within evaluations." "Issues around ensuring participant consent and strategies for ensuring that results are reported to participants are understandable by all." "Getting IRB approval and appropriate informed consent." "The challenges to including individuals with cognitive disabilities in evaluation are: (1) Ethics - ensuring those individuals are not coerced to participate or respond in a certain way; (2) Accommodations – understanding and implementing accommodations for participation; and (3) Resources - limited financial and human resources to implement accommodations."
Proxies	"Determining when proxies or interpreters should be included can be a challenge. In addition, experts in communicating with individuals with cognitive disabilities should be consulted when data collection protocols and instruments are designed." "Depending on the disability, fatigue may be a bigger issue or really working to ensure my questions are clear. My biggest challenge though is convincing care-givers and providers that I really do want to talk to the person with the disability -- I don't want to talk to a proxy. I have had some respondents who were nonverbal and that was difficult to make sure I really know what their answer was."

Additional comments

One of the last survey questions asked participants if there was anything else they wanted to share about themselves or their experience working with IWCD. Some participants shared further details about the evaluations projects they have worked on; others shared details about family members who have a cognitive disability. Several participants chose to clarify or explain their earlier responses, and a few made negative comments about the questionnaire, such as the use of “jargon” or that they did not understand what was considered a “cognitive disability” (suggesting they may not have read the survey introduction). Other participants, however, mentioned how much they appreciated that the study is focusing on IWCD in evaluations and that completing the survey made them think about how to include a group they had not previously considered.

Interview Responses

This section presents the themes and relevant examples from the 12 interviews conducted with evaluators who work with IWCD. (See Chapter 3 for details on participant selection). The interviews ranged in length from 20 to 63 minutes, with an average of 38 minutes. The final sample included 3 participants who are either directors or evaluators at a UCEDD.

Background

As of April, 2014, 5 of the participants were members of the Disabilities and Other Vulnerable Populations TIG at AEA, and one participant was a former member. All but one participant was a member of AEA at the time of sampling. Eleven of the participants have a doctorate and the remaining participant has a master’s degree. Table 14 provides a brief profile of each interview participant based on their survey responses.

Table 14

Background Details of Interview Participants

					Data collection methods used with IWCD					
Participant	Gender	Years as evaluator	Self-classification	Types of programs evaluated in last 5 years	Individual interviews	Group interviews	Focus groups	Obser-vations	Question-naires	Psycho-metric testing
Participant 1	Female	15+	Primarily an evaluator	Education	✓	✓	✓		✓	
Participant 2	Female	15+	Equally a researcher and evaluator	Nonprofit, Social Service (government run)	✓	✓	✓	✓	✓	✓
Participant 3	Male	15+	Primarily an evaluator	Education, Nonprofit	✓			✓		
Participant 4	Female	10 to 14	Equally a researcher and evaluator	Education, Nonprofit, Social Service	✓	✓		✓	✓	
Participant 5	Male	10 to 14	Primarily an evaluator	Education, Nonprofit, Social Service, Health Care	✓	✓	✓		✓	
Participant 6	Female	10 to 14	Primarily an evaluator	Nonprofit, Health Care	✓				✓	

Background Details of Interview Participants

					Data collection methods used with IWCD					
Participant	Gender	Years as evaluator	Self-classification	Types of programs evaluated in last 5 years	Individual interviews	Group interviews	Focus groups	Obser-vations	Question-naires	Psycho-metric testing
Participant 7	Female	15+	Equally a researcher and evaluator	Nonprofit, Social Service, Health Care	✓	✓	✓	✓	✓	
Participant 8	Male	15+	Primarily an evaluator	Nonprofit, Social Service, Health Care	✓	✓	✓	✓	✓	
Participant 9	Female	5 to 9	Primarily an evaluator	Education, Nonprofit, Social Service, Health Care				✓	✓	
Participant 10	Male	15+	Primarily an evaluator	Education, Nonprofit, Social Service, Health Care	✓		✓		✓	
Participant 11	Male	15+	Primarily an evaluator	Education, Nonprofit, Social Service, Health Care	✓	✓	✓		✓	✓
Participant 12	Male	15+	Equally a researcher and evaluator	Education, Nonprofit, Social Service, Health Care	✓	✓	✓	✓	✓	

The interviewees participate in a range of evaluation activities with IWCD. While all interviewees have some experience collecting data from IWCD, their current roles vary. Most participants still conduct evaluations in which they are working directly with IWCD. A few participants do evaluation capacity building with organizations that serve IWCD, instructing staff on appropriate accommodations and helping with the development of evaluation designs and instruments. One participant who works in the K-12 education system mentioned that he/she has the school staff do the actual data collection in most cases. A few participants now work in a management role, overseeing the evaluations rather than doing the on-the-ground work themselves. Despite these different evaluation roles, all interviewees had enough experience in both evaluation and working with IWCD to be able to provide meaningful responses to the interview questions.

The researcher began each interview with several questions about the participants' backgrounds, such as how they came to conduct evaluations with IWCD, how many evaluations they have conducted with the population, and describing the populations they have worked with in terms of age, type and severity of disability, and evaluation context. Although many of the background details the participants provided cannot be shared to protect confidentiality, the background information helped the researcher to determine what prompts to use during the interview and which questions were not relevant.

Most of the participants worked in the disability field, either through direct service or as part of their graduate education, before working in evaluation. For example, one participant began as an occupational therapist and another as a special education teacher. Only two participants started with an evaluation and research methods background and then moved into evaluating programs for IWCD. The number of evaluations that participants had worked on with IWCD ranged from about four to over 100. The variation in number was a reflection of both age (some participants were retired) and how recently they had started working in the evaluation field.

The interviewees conducted evaluations with individuals with a wide range of cognitive disabilities and across the lifespan. All interviewees mentioned working with individuals with at least one of the following cognitive disabilities: developmental disabilities, traumatic brain injury, Alzheimer’s disease, Asperger’s syndrome (autism), and severe mental illness. Participants worked with elementary school children and high school and college age individuals, as well as with older adults. All of the participants conducted evaluations with programs that specifically serve individuals with cognitive disabilities. About half mentioned also evaluating programs designed for the general public that included IWCD, such as programs focusing on homelessness or substance abuse. Several of the participants also conduct evaluations in which IWCD are not a focus. The interviewees described the range of the disabilities in the individuals they have worked with from mild to severe, and several mentioned that they have conducted data collection from families, teachers, and care-takers in cases where the IWCD were not able to participate directly.

Interview Themes

This section presents the themes and representative quotations from the 12 interviews. Much of each interview focused on the process of the evaluation, including methods the respondents use with IWCD, the accommodations they have made, and the benefits and challenges they have had when working with this population. The interviewer asked all participants about their use of proxies and how they make decisions to include or exclude IWCD from evaluations as participants, as well as about working with IRBs and obtaining consent (see protocol in Appendix B). The interviews also included discussions around inclusion on the evaluation team and the relevance and future of inclusion in the evaluation field. A summary of the themes the researcher extracted from each topic is provided in Table 15.

Data collection. The interviewees mentioned using all of the typical data collection methods in the evaluation field, including interviews, focus groups, surveys, using student data, and document analysis. Most used methods that could be conducted in person, although one interviewee mentioned using electronic surveys with individuals with mild cognitive disabilities. One participant explained,

> We try to interview people with intellectual disabilities in person and one-on-one as much as we can. So sometimes, even if we're interviewing other people by phone, we'll try to do an in-person meeting with the person with an intellectual disability. Doing -- oh, like I said, one-on-one as much as possible as opposed to focus groups or something. Doing interviews instead of written surveys. (Participant 4)

Table 15

Summary of Themes from Evaluator Interviews

Topic	Themes
Data collection	Prefer in-person Common evaluation methods Use visual imagery Select method by ability Collaborate with IWCD, staff or other advocates

Summary of Themes from Evaluator Interviews

Topic	Themes
Accommodations	Universal design Attempt multiple approaches One-on-one In-person Read aloud Extra time Confirm results Check completeness
Sharing results	Universal design Copy data collection accommodations
Challenges	Time and money Limited experience with IWCD Need to accommodate for multiple needs May not know enough about the disability Locating participants Gatekeepers Acceptance of work by peers Limited benefits for IWCD
Benefits	Opportunity for socialization Having a voice/being heard Opportunity to influence change Evaluator growth
Proxies	Prefer direct contact Good alterative Provides voice to IWCD Validity concerns - Subjective vs. objective data Triangulation
Decisions about inclusion	Target populations Include in some components Increased awareness of accessibility needs
Consent and IRB	More communication with IRB Manageable challenge Create challenges for accommodations Simplified consent process Continual consent

Summary of Themes from Evaluator Interviews

Topic	Themes
Inclusion on team	Participatory approach Collaboration is essential Beyond tokenism Provide evaluation training Make accommodations Receive support from family or advocates Adds time and money
Inclusion in the evaluation field	Part of diversity IWCD are in many programs Universal design benefits everyone Reduce marginalization Increase validity Low visibility at AEA Increase access to education

One participant mentioned using lots of performance and pictorial methods such as photos, videos, and icons when collecting data from individuals with developmental disabilities. Most of the participants had used some sort of visual imagery to assist in data collection. No participants discussed using observation, although one participant mentioned "field testing" the use of iPads in one study. Participants mentioned the challenge of determining the appropriate method for the population and the appropriate individuals from whom to collect data. One evaluator said,

> I would say sending them [an] electronic surveys, except for the folks with traumatic brain injuries, so relatively high-functioning -- electronic surveys are not going to work so well. I think, too, folks with developmental disabilities and cognitive issues, it is essential to sit down and talk to them face-to-face. That, of course, makes it more expensive. Sometimes a focus group can work, but it really requires that you have somebody who's actually experienced in working with folks with developmental disabilities, have hand-on experiences in other situations, like service delivery. And that's probably my bias. I think many of the people who go to do this work think, well, it's just another group, I'll just go talk to them… I think it's important for them to have some feel for who you are and

> not that you're just some stranger that's walking in. I think it can be really difficult. The results are going to be very skewed. (Participant 7)

Participants discussed the importance of collaborating with program staff and IWCD or their advocates to determine the most appropriate methods. The evaluators also asked those individuals with assistance in developing and piloting the data collection instruments. For example,

> Well, I think it's the same as with any evaluation. It's trying to make sure that the tools -- so, like, our surveys and our focus groups questions -- are meaningful to people of that population. And so it's getting away from terminology and jargon and trying to write things that make sense from their perspective. So we do a lot of pre-testing and cognitive interviews on our tools beforehand with that population. And usually, we're working with, like, advocacy groups or -- so for the evaluation with children, we work with the [State] Federation of Families for Children's Mental Health. And so they have a good perspective on how things will relate to family members and to youth. So we work collaboratively with our stakeholders to make sure that those tools are meaningful. (Participant 11)

A few evaluators used data collection methods to gain feedback on their process and instruments. The evaluators often piloted the instruments with IWCD to ensure they were accessible, although such piloting did not always catch all possible obstacles for the range of people that would be participating. One participant used focus groups throughout the process and explained,

> We do a number of focus groups when we plan programs, like programs for aging, where we bring in individuals with disabilities and ask them what their needs are and their priorities and then, after we set up a program, we follow up with them to, you know, see how effective it was. (Participant 12)

Other participants also mentioned having service professionals collect the data rather than collecting it directly. In some cases, the data collectors were teachers or staff members who were already familiar to the individuals. In other cases the data collectors were other

IWCD or people with more experience working with the specific population from whom data was being collected.

Accommodations. The interviewees mentioned many different types of accommodations that they have used with IWCD. There was often similarity in the accommodations across methods. Interviewees mentioned using accommodations from universal design, such as larger print and simplified language in instructions, questionnaires, and other materials provided to the participants. Universal design involves making products or processes accessible to everyone so that special accommodations do not need to be made for certain individuals. Many interviewees mentioned using emoticons or other pictures that the participants can point to or arrange to communicate their answers. One interviewee mentioned using flip-charts with pictures during focus groups to help the participants provide responses:

> I had a protocol. And I used a flip chart and kind of -- and again, these sort of emoticons, you know, that would indicate, you know, I'm satisfied with the opportunities I have. I'm not satisfied with the opportunities I have. I would ask for a show of hands. We went around the room. We had a lot of opportunities for others to encourage their peers to respond. And some helped others respond. (Participant 10)

Sometimes the evaluators needed to simplify the language or concepts in an existing instrument. When developing surveys, participants used fewer options and would often pair pictures with those options. One interviewee described how he has needed to modify surveys for IWCD:

> For this population, and for others, in order to diminish the size of the survey, I've oftentimes gone through, chosen two items that either have the greatest reliability statistics and therefore may be the most indicative -- anybody with a background in survey research would cringe at what I'm saying. But I would take just two of the most indicative items of that survey scale and include those in the survey instead of administering the entire survey scale. And I would use those two items

> as a proxy for the entire construct. And I can get away with that in evaluation because I'm providing -- I'm providing as-good-as-it-gets feedback to the program staff so that they can make changes. That's, you know, certainly not to diminish rigor of evaluation in comparison to research, but it's certainly a limitation of the work that I've done. But it's a necessary one. (Participant 5)

As this participants noted, these changes could be seen by others as reducing the reliability of the measure, but the participants argued that they are more reliable and valid than using a measure that is too complicated for the individual completing it.

The evaluators also paid attention to the length of the measures since data collection with IWCD can be slower and participants may become tired or have other time constraints. When conducting interviews, one respondent explained that the interviewers will prioritize a few of the most important questions to ask the participant and will then skip later questions if there is no more time or the participant is becoming frustrated or fatigued. One participant mentioned conducting multiple interviews with a patient with traumatic brain injury to allow the participant to process thoughts and obtain the information needed.

Similarly, the most common types of accommodations that the interviewees reportedly made related to how the data were collected rather than actual modifications to instruments. Some participants explained that they do not have multiple forms of an instrument for individuals with different cognitive abilities, but they do alter the procedures as needed for each individual. For example,

> … sometimes you have to try several things before you get something that they can really respond to or they get the direction. So I think somewhat a trial and error. And then, you know, understanding what disability they have and thinking, okay, what are their strengths to respond to or to understand and then play into that. (Participant 2)

Again, evaluators felt it was important collect data in-person, even if the measure would be done online or on the phone in other circumstances. One participant explained,

> I think it's important to measure everything you can. And what's difficult to measure sometimes is the most important. And it could only be done in a face-to-face situation, I believe, to get a sense of whether the person understood the question or not. (Participant 10)

Participants mentioned the additional time required when collecting data from IWCD. Many interviewees mentioned reading the instructions and questions out loud to the participants, often one-on-one. For example,

> I think we accommodate through giving people a lot of time to participate in our administration instructions and our administration. We will read out -- you know, we'll go through the survey as a whole group, read out all the questions so that people can kind of follow along as they go. (Participant 9)

Participants discussed the importance of ensuring they are correctly interpreting the responses they receive. A few evaluators mentioned the importance of using triangulation with data from other sources to verify they had accurate data and interpretations. They also would confirm their understanding with the evaluation participant. One participant described the detailed process they go through to ensure they are obtaining accurate responses from IWCD, stating,

> We were very careful about our implementation protocol… We would sit down with each student and…we'd repeat each question. And then, for multiple-choice ones, we would read the choices once and then read them again because it's very hard for anyone to keep all those responses in your head, you know? For… agree/disagree…we'd ask first, do you agree or disagree. And then once they said … we would say a lot or a little to get, like, strongly agree for versus strongly disagree ... And then, for every response they gave us, we would repeat the response back and ask … is that the one you meant? And they would either say yes or no. If they said no, we'd have to repeat it again. (Participant 6)

Another accommodation that participants made was monitoring the way they behaved when collecting data. Several participants mentioned the problem of acquiescence. For example,

> …people forget that with folks with developmental disabilities, the way you ask the question, the way your face looks, how you interact with them, they're looking for cues, in some instances, to satisfy you. So if they think you want a negative answer, they're going to give you a negative answer. Or if you smile and [act] happy, they may think that everything needs to be positive. With folks with traumatic brain injury, I think -- and with -- well, not so much with -- it varies a little bit by disability, but folks with traumatic brain injury, I think it's really important to allow them the time to provide [answers]… We tended to use a talk story method of getting information from people. They're allowed to sit and discuss it, and it becomes familiar in many ways. (Participant 7)

Interviewees also mentioned conducting interviews or other methods in locations in which the IWCD would be more comfortable. They provided questions ahead of time, particularly for individuals with disabilities from stroke or TBI, allowing those participants time to formulate their responses. Sometimes the accommodations involved simply being more observant of the data being collected. For example,

> …One of the things I've noticed is that I have to be really diligent in looking at survey responses. Because I've noticed with the population of students with disabilities -- and I'm assuming that includes those with cognitive disabilities as well -- I have to be really diligent about going back and seeing whether they have completed the entire survey or just answered the first five questions and clicked submit and they were done. (Participant 5)

Several evaluators mentioned that on occasions when they have not done the data collection one-on-one with IWCD, the measures are often left incomplete. This is not dissimilar to measures conducted with any individuals these days.

Sharing Results. Most of the evaluators make their results available to the participants, particularly if the participants request access. The way those results are made accessible to IWCD varies, although many use the principles of universal design or use similar accommodations that they used during the data collection phase. A few interviewees described cases where the programs took the evaluation report and made a simplified report for the evaluation participants. One evaluator described making a two-page handout for participants, and another mentioned using video to convey the results. Some evaluators said they had not worked to make reports accessible to IWCD or that they need to work harder to do so.

Challenges. Closely related to the accommodations that the evaluators have made for IWCD are the challenges they have faced when working with this population. A few participants commented that the challenges are really similar to challenges they would face in any evaluation. Many interviewees mentioned challenges related to data collection. Some commented on the additional time involved when working one-on-one to collect data, as well as for the additional meetings when conducting participatory evaluations. For example,

> I would say collecting data from them, collecting data with them. You know, it just is an abstract enterprise. And, you know, if you think about numeric data, and if you think about sensory data, and if you think about cognitive representations and schema, you need to be very patient with individuals. So one of the issues is the time scale of the project. You know, what you and I would refer to as, let's say, pre-evaluation assessment and evaluability assessment, I find you have to stretch those periods out because they involve a lot of training of people and preparation of people to get to the kind of validity that you want in an evaluation. (Participant 8)

One evaluator mentioned that often participants just want to talk and that can make the process much more time-consuming. The additional time translates to additional money. A few participants mentioned that their funders do not always want to cover that additional expense, although the majority of funders are focused on the disability field and were therefore supportive of the evaluators' efforts to be inclusive.

Several evaluators found modifying instruments and data collection procedures challenging. This challenge was exacerbated in cases in which the evaluator or data collectors had no experience working with IWCD. Evaluators found some questions difficult to simplify. A few evaluators mentioned that they found acquiescence a challenge to work with. Evaluators also struggled to make sure the questions were clear, particularly when collecting data from individuals with many different disabilities. In some cases, the evaluator has no idea what disability a participant has or the severity of the disability and cannot prepare ahead of time. The challenge of including individuals with different disabilities and different degrees of disability exists for both the evaluators and the participants. One evaluator explained,

> I think it can be frustrating if people -- like, for example, in one of the projects, I can think, where there's mixed groups and people -- there's the people with the physical disabilities that don't have the cognitive disability that may be going at a much faster pace. So it may be frustrating for not being able -- not being at that same pace or feeling like it's taking longer. (Participant 9)

A few evaluators mentioned that they often are not sure if their questions worked or not; they are not sure if the problem is with their data or with the program. In other cases, the evaluators struggle to simplify the language when evaluating complex programs or policies. For example,

> In particular […], since we're often studying policies or programs, it can be difficult to bring the questions to a level that's cognitively appropriate for individuals with cognitive disabilities. So, for example, we might be asking a policy question, but we really need to think about how to bring that down to the individual level because if it's too cognitively challenging to ask them to really comment on a policy or approach -- a government program, say. It's easier when we're studying a particular, like, on-the-ground effort, like a training program or something, and we can ask -- we ask them about their experience with that program... And finding someone with an intellectual disability that's even following that issue and understands implementations of that high-level policy can be challenging. (Participant 4)

Another challenge is reaching the target population. There is usually no database of IWCD who are interested in participating in evaluations, and some IWCD who are more easily reached feel over-surveyed as there are multiple groups trying to reach them. In some cases, the evaluators met resistance toward the evaluation from the program or service providers. One evaluator described a situation where the service providers did not feel a survey was sensitive enough to the particular needs of the different respondents and did not want to take the time to get accurate responses. Another interviewee described a situation where the evaluators were trying to be inclusive by collecting pictorial responses, but still not everyone could finish within the time allotted by the staff and therefore could not participate fully.

A few participants mentioned the challenge of getting other evaluators and researchers to accept their work as sufficiently rigorous when they make alterations to existing measures or when they make different accommodations for different participants. One evaluator explained,

> Sometimes people get really picky about making modifications and want to discount the results of the research because it wasn't -- it's something that should be administered in a particular way, then -- and you modify that way, then they say, well, that negates your instrument… But that's the only thing is just the acceptance of modification by the research community. (Participant 2)

In a separate question, the interviewer asked the evaluators if they ever felt that IWCD were harmed in any way by participating in an evaluation. This question was asked due to the history of this population being mistreated and misrepresented in research. Most of the participants could not think of any way in which their participants have been harmed, stating that their participation in activities such as completing surveys or participating in focus groups was fairly brief and did not cover personal topics. A few mentioned that as part of their IRB requirement, they have a counselor available to speak with the participants if the evaluation brings up an difficult issues for them, but that they have never had to utilize that resource.

A few participants did identify ways in which they feel IWCD might be harmed. Two evaluators mentioned that the evaluations may not really benefit the participants. One explained,

> You know, I think one of the issues with any of the projects and any of these school reform efforts, there's a lot of data tracking, whether students have disabilities or non -- or non-disabled. And, you know, I think there are -- I'm not so sure about the benefits, really, to the students. I think there are definitely some downsides to -- for data collection and surveys to the students and just sort of the burden on them. And, you know, I think they can be anxiety-producing, you know, depending on the type of student and, you know, if they don't test well and all that kind of -- you know, those kind -- those aspects of assessment. But it's built into just about every project and every grant and any kind of -- you know, any school has a certain level of investment and accountability. (Participant 1)

And the other stated,

> I also feel like there's a little bit of me feels like I'm using them because I get the publications. I get the research. You know, I get the funding. I've got a beautiful life. And, you know, their life is pretty sucky sometimes. So there's that whole sort of sense of really feeling like perhaps we -- you use them. (Participant 2)

A few participants explained that harm that may come if the data collectors are not experienced in working with IWCD. For example,

> I think if you have people who do not understand working with people with disabilities, they can talk down to them. And let's face it, people with disabilities are people, and they understand when other people are treating them in a fashion that makes them feel less than or not treating them with what they say as being truthful or factual. Being questioned about whether it really happened or whether this is really true. Saying that they're going to involve people in the participatory process and then they don't or that they're going to be involved in an organization and not be treated as an equal. It can create very harming histories, you know. (Participant 7)

Benefits. All participants were asked what they feel are the benefits of including IWCD in evaluations. Some evaluators discussed the importance of IWCD having the opportunity to participate fully in their communities and to influence how programs and policies are developed. Evaluators felt that IWCD appreciate being able to have a voice and feeling that they are being heard. One evaluator explained,

> I found it very interesting, from one of the focus groups, that -- of course, this is something that also, you know, there's a little bias, in the service providers always bring their best people forward, it seemed like, for the focus groups. Not always. There were a couple of characters that really had -- that were challenging. But in one particular focus group, it really came out that the individuals wanted to participate to help their peers. They were very proud of being able to be a resource for their peers to help their peers' voice be heard or provide other information that might help them in the long run. And they definitely wanted to show other people in the community that they could contribute to the community -- entire community, not just their culture of individuals with developmental disabilities. (Participant 10)

A few evaluators commented that IWCD can benefit from evaluation by being introduced to other individuals who have similar experiences or interests, particularly in the case of focus groups. This is also a benefit for care givers who may participate in focus groups.

Several evaluators shared experiences in which they felt one particular individual really benefited from participating in the study. Those specific stories are not shared here to protect confidentiality, but the general theme is that these individuals had the opportunity to feel someone was really listening to them. In the case of a woman with TBI, she had some time to process her thoughts about her current situation and to tell her story. The evaluator explained,

> I think there's been a number of times where people have felt grateful. And sometimes it takes a lot longer to collect data from individuals because they want to talk, too. And I always tell -- if I have people helping me collect data…that's part of their payback, if you will, for participating in this, is to let them tell their

> story, to let them talk it through, to -- you know, just be supportive of them. (Participant 2)

Other examples were situations in which a personal problem an individual was having was revealed during an interview, and the interviewer was able to bring that issue to the attention of program staff so it could be resolved without the participant being put in an uncomfortable situation.

The evaluators also spoke of how working with IWCD benefits them personally and professionally. They referred to the benefits of being able to collect data directly from the individuals, without the biases of care takers interfering with the data. Participants spoke of learning about effective ways to communicate and share with IWCD.

Proxies. The researcher asked each interviewee about whether they have ever used proxies and, if so, the benefits and challenges related to their use. The majority had used proxies at least once, particularly with individuals with severe cognitive disabilities and in situations where the data collection would be too intrusive to the IWCD. Common proxies included service providers, family members, teachers, guardians, and advocates. The evaluators emphasized that their first choice is always to collect data directly from the individuals, but proxies provide an alternative means of including the voice of IWCD when necessary. One interviewee said,

> On occasion, you may need to ask a parent or a service provider. I've had to do that. And what I will say is, given that this is not a survey for you, I want you to step into this individual's shoes and speak from the way they look at the world and not the way that you see it. And that has -- that's better than nothing if that person is unable to communicate well or has limited language skills. (Participant 7)

Another participant described the rationale for using proxies on an upcoming project, stating,

> It's looking at quality of life for people with different disabilities, including cognitive disabilities, and [the clients] felt that if we didn't use proxies for people with the most severe disabilities, their voice would not be heard through the process, and they -- it was very important. They felt like they were some of the most marginalized groups…If they can't take that survey tool, they want somebody to be able to take it on their behalf that's the closest person to them. (Participant 9)

Several evaluators emphasized that they always try to get individual to respond first and, if they are unable to participate, then turn to a proxy.

Although the evaluators considered proxies a valid data source, the evaluators cautioned that it is important to have a proxy who is an advocate for the individual and who will truly focus on what they believe the individual with the disability feels without inserting their own feelings and biases. A few evaluators said they have had cases where the proxies' responses conflicted with the participant's responses, in which case they either have to decide which to take or to take both in qualitative data. Some evaluators mentioned that the proxies were more useful for the objective measures than subjective. For example,

> … I think our sort of confidence in the results was less in terms of the more subjective measures than it was the objective measures…I think it's really important to try to work with the individual. You know, if you've got a face-to-face situation when you're collecting data from them, it's really important to try and not use the proxies just because it's [so much] easier. Especially, again, on the subjective measures. Like, I did a lot of research on quality of life. And, you know, that's a subjective measure, but we could [ ] use happy faces and, you know, simplify the language and work with them to kind of try to elicit that -- some of that subjective data… And I had many, many instances where the proxy, who may be watching, who may be there, saying, 'Wow.' You know, they had never really tried to understand or had just assumed some of these kind of things…I can think of several particular incidents where the proxy would be either blown away or kind of surprised by the higher quality of life or lower

> quality of life, especially on those kind of measures, that the person, you know, would respond that they have. It wouldn't be a conflict, but a surprise. (Participant 2)

Another evaluator explained,

> I think it was helpful in that these were people that otherwise just couldn't have participated at all. But you also need to sort of take anything that a proxy says with a grain of salt. And I found that to be particularly so with staff because I think they have a bias, of course, to think that they're doing the right thing by the person. So always having to have that in mind when looking at that information, that you're not hearing from the person directly but hearing sort of indirectly from someone who has another stake in the service being offered. It's better than nothing, but it's not perfect. (Participant 4)

Again, some of the interviewees, including those who had not used proxies, mentioned that they do collect data from family, service providers, teachers, etc. to triangulate the data. Those close to the individual with a cognitive disability can help to fill in some of the gaps. They can also help verify that the data the evaluator collects from either the IWCD or the proxy are accurate and are being interpreted correctly.

Decisions about inclusion. Related to using proxies, the researcher asked each participant how he or she decides to include or exclude an individual with a cognitive disability, or if he or she has ever intentionally excluded IWCD from an evaluation. None of the participants could think of a time when they intentionally excluded a participant, although in some cases they did use a proxy instead of going directly to the individual. In almost all cases, IWCD are the target population of these evaluations, and so the evaluators expect to include those individuals. There were some instances in which the participants were unable to participate in every aspect of the evaluation, but they were still included in some components. For example,

> Well, I would say, for -- in the instance with the kids with the most severe disabilities, we -- they could not respond to the survey, so they didn't take the

> survey, but they were included in other aspects about attendance records and some other things that they would have to gather information from. So we made the call that they could not respond to those questions, along with their teacher. And so they were not included in that aspect, but they were included in others. (Participant 9)

A few evaluators noted that there have been times when they wished they could have excluded certain individuals who were really difficult to work with and disruptive to the group, but they recognized that such situations are just part of working with some populations.

As many of the interviewees conduct evaluations on programs for the general public, not just on programs focused on disability, the researcher asked to what extent they have considered including IWCD in those evaluations. The evaluators felt that they are more aware of the possible presence of such individuals in the population than their peers who are not involved in the disability field. However, none of the participants said they make extra efforts include IWCD, unless they were are a target population of interest. For example,

> And I'm thinking about it from a practical dollars-and -- yeah, dollars-and-cents sense. I don't know if I would unless it were something that I knew that would -- that was specifically targeting students or other people with cognitive disabilities. And the reason is -- so, I mean, if your work is sort of a broad-scale evaluation that targeted -- so most of my evaluation work -- well, all of it -- deals with diversity of some sort. So it would mean hearing not only from those with cognitive disabilities but also the potential -- the population of students with other disabilities as well, along with those who would -- who represent other diverse groups. So all my racial and ethnic category -- gender as well. If I were to do that, my number ramps up dramatically. (Participant 5)

Instead, some evaluators discussed trying to make their evaluations accessible to as many as possible, including IWCD and those with limited English, by keeping questions at an easy reading level and having multiple ways to collect data.

Consent and IRB. The researcher asked each participant about his or her experiences with Institutional Review Boards when conducting evaluations with IWCD. All but two evaluators said that they usually or always go through IRB for their evaluations with IWCD. One of the two evaluators is based at a university, but said all the evaluations are considered exempt. The other was not based at a university and has not needed IRB approval on projects. The 10 participants who do usually go through IRB are based both in and out of university settings. Those evaluators had mixed experiences with IRB. A few evaluators said they have never had any issues getting through IRB. Some evaluators found that they must communicate and explain more to the IRB, particularly when they are required to go through full review. For example,

> It makes the process a little more time-consuming because certainly we come under more scrutiny for [including IWCD]. I don't think it's really prevented us from doing anything in the long run, but it sometimes is just a lot of paperwork and back-and-forth… You know, we have a lot of studies that would probably be even -- everything has to go through the full IRB if there's people with intellectual disabilities here, and we have a lot of projects that probably wouldn't be full IRB if it weren't for that… And the IRB tends to require a lot of sort of legal language that makes it difficult to really simplify it down to an accessible level without explaining it. (Participant 4)

One evaluator mentioned the challenge of trying to simplify some of the legal language the IRB requires for the consent forms, but eventually being able to get the IRB to compromise. In another situation, the IRB wanted to restrict the number of proxies the evaluator could use to obtain sensitive information about an individual. One participant expressed frustration with the IRB requiring all members of the evaluation team to have completed human research training. While she has wanted to include IWCD and individuals with limited English language skills on the evaluation team, she found that the human subjects requirement was a hurdle they could not overcome. The degree of scrutiny and type of review required depending on the IRB members, and evaluators were aware that the requirements and issues might be different in future projects.

Whether or not the projects received full IRB review, all interviewees obtain consent or assent when collecting data from IWCD. The method of obtaining consent varied by project and evaluator. A few evaluators had written statements that they read aloud informing participants that by continuing they were consenting to participate. Most evaluators obtained verbal consent, and some also obtained written consent. Evaluators described the consent process as being more challenging when working with IWCD. For example,

> Well, it's more work to make sure that you -- those individuals clearly understand the purpose of what you're doing, are able to respond with ease, that they don't feel like they're obligated to do something that they don't want to do. (Participant 12)

To ensure clarity, the participants made a number of accommodations during the consent process. The most common accommodations were to simplify the language, use larger print, and to read the consent forms with the participants. One evaluator described using audio, video, and a comic book to explain the consent process to IWCD over many evaluations. Another evaluator described a two-step consent process where the evaluators first explained consent over the phone when arranging participation, and then reviewed it again in person. When collecting data from minors or individuals with guardians, evaluators had the guardians sign the consent form and obtained verbal assent from the children. Several interviewees described reminding the participants throughout the data collection that it was optional and they could stop any time or choose to not answer certain questions. One participant explained,

> I have written forms and all that kind of stuff that you have to have for your IRB. But, you know, you can't give somebody a form and say, “Is this okay?” You have to really explain it to them. And I also tell my research assistants, you have to make sure that they understand. It's not -- and that they really get it. So if it takes you 20 minutes, then make sure that they understand that this is voluntarily, that they don't have to do it. And that they cannot answer questions and all that. So you simplify it and at least get a nod or, you know, a yes or no, if you can give them the words to point to, or a head shake or, you know, some kind of indication that it's okay to move forward. (Participant 1)

Overall, participants felt the consent process was both extremely important and manageable when working with IWCD.

Inclusion on the evaluation team. The researcher asked each participant if he or she has ever included IWCD on their evaluation teams in any way, e.g., as consultants or co-evaluators. Almost all of the evaluators had included IWCD in the evaluation process through participation on an advisory board or steering committee. Many evaluators mentioned that such inclusion was inherent to the participatory evaluation approach they take in their work. Describing the importance of participation, one evaluator said,

> So two main things: One is that their participation, in and of itself, is going to make this a better evaluation. Like, there's just no way I can know the types of things that they suggest and they point out, they think about are things I would never think about. So they make it a better evaluation, which in turn is going to make the programs that are serving them better. And then -- so in that way, it benefits them. And then, two, like, we really think about, in all of our evaluation, that it's a capacity-building experience. And so I think just having that time, I think, for anyone learning the skill to think, like, evaluatively about things is helpful. To think, what do we want to know? What do we want to learn? How would we -- how would we capture that data? And then to sit down together and look at the data and interpret it together, I think, is extremely valuable for anyone taking part in that. Because it's just sort of a different way of looking at the world, and -- yeah. So it's a great learning thing, but I think the evaluation itself is just much better for their involvement. (Participant 6)

However, no evaluators had worked with a co-evaluator who had a cognitive disability. The one interviewee who had not worked with IWCD on an advisory board or steering committee reflected that such participation would have been beneficiary had she thought of it. All evaluators have had IWCD, whether on a committee or not, review and give feedback on instruments. Many interviewees could not imagine doing evaluations without their input. One evaluator said,

> We work collaboratively with our partners, and so we do participatory program evaluation. So we have usually, like, an advisory committee or a broader stakeholder group that we're working with. And so with them we review tools and approaches, and then they help us in data interpretation and wording results so that it will be meaningful to our target populations, which include those consumer groups. So I would say we haven't done any evaluations in the disability area without including them... I don't think our evaluations would make any sense without them. Because they keep us grounded in what the -- what the issues of focus are. They help us define what those specific evaluation questions are that we want to answer. They also help us in identifying tools that re relevant and not overly burdensome for people participating in the evaluation. They help us on the interpretation because they've lived that experience. And then they also help us target who needs to get the information. So -- and that's not only individuals with cognitive disabilities, but also policymakers that would have an impact on services for that population. (Participant 11)

The evaluators stressed that the participants should not just be token members of the committee, but should be able to actively contribute and have some understanding about the evaluation process. Another evaluator discussed the importance of involving IWCD in evaluation capacity building efforts as well, explaining,

> I think a capacity -- when you're talking about individuals with disabilities, at least from my perspective, is that those individuals themselves and those individuals that are closely aligned with them and helping -- and helping them making life decisions and so forth must be involved in the process of evaluating any kind of programs and services. So the notion of a capacity-building -- not only the people who run the project or the managers or the policymakers or the people who are funding, but the parents as well as the individuals with disabilities need to be involved in understanding and building, you know, any type of evaluation design that attempts to evaluate, you know, the merits or the work of the programs and services or how it's helping -- benefiting individuals with disabilities. (Participant 3)

The evaluators made a number of accommodations to ensure the participation of IWCD in the evaluation process. Some of these accommodations were the same as are done during data collection, including assisting with transportation or meeting at a location convenient for the individuals, making documents more readable, and making documents accessible for those who cannot attend a meeting or need to review the documents ahead of time. For example,

> I would say a lot of it is that sort of extra support from somebody else on the teams, doing things like preparing for meetings ahead of time. So for example, we had somebody on the advisory board who had some -- a couple of people that had some cognitive issues where we'd always have myself and another staff member sit down and go over the agenda with them ahead of time and talk through their thoughts and then sort of help them to speak up in the meeting. Because one of the challenges was that, in this big group meeting, the ideas would fly fast and furious, and they just couldn't keep up. So making sure that they had their thoughts formulated ahead of time and their voice was heard, I think, was something that was a challenge but something we found an effective solution for. (Participant 4)

One evaluator mentioned that the individuals could assign a proxy to help make decisions around the evaluation. Some evaluators had the individuals bring family members or other advocates with them to help share their perspective. Evaluators also work to help IWCD understand evaluation practice. Several evaluators mentioned doing some basic evaluation training with IWCD and their families so they could better help with the evaluation design, instrument development, data collection and interpretation. For example,

> And then I articulate the evaluation from their perspective and what they want to achieve. And oftentimes, that does require some modification of materials -- modification of my own language introducing people to the nature of evaluation, linking evaluation to their worldview and their perspectives and their emotional concerns about the situations they're in. So it's not unlikely I'd be working with people who are very assertive but may not have all the tools that the mainstream environment may say is required of someone engaging in something we -- you or

> I would refer to as evaluation. And then I try to bring people into roles as evaluators -- into the different phases of evaluation. Particularly in conceiving of sort of the values that are going to serve as the basis of judgment of a given object if that's what we're doing... I just don't [want] them to be involved as -- so we can assert -- I can assert that they were present, I want them really to be making substantive decisions about the direction -- the nature and direction of the project. (Participant 8)

A few evaluators commented that since there are usually people in participatory evaluation projects who are unfamiliar with evaluation, they always need to help the team understand the purpose and process of evaluation, and so the participatory process with IWCD is not that different.

Several challenges were mentioned when working with IWCD on the evaluation team. As with data collection, the biggest challenges were related to time and money. Evaluators noted that they generally do not have money to pay the members of the advisory board, so it can be difficult to get people to join. They also mentioned not having the budget to spend time making all of the documents related to the evaluation, including training materials, accessible. One evaluator mentioned that since many IWCD do not have cars, there can be transportation issues, and they may miss meetings. Another evaluator mentioned the problem of competing agendas on the evaluation team, stating,

> There are cultural differences, and there are different understandings about disabilities. And so different people have a different set of values. And so the challenge was to be fair and to try to get a blend of their values in regarding data, trying to avoid bias or preference of individuals. Different people had political agendas sometimes, trying to push or -- you know, a strong advocacy in certain areas. And when we were doing these evaluations, we tried to encourage them to recognize those -- their position as well as other positions and getting multiple voices involved in trying to answer any of the evaluative questions or determining criteria, and especially in writing up the results. (Participant 3)

Despite these challenges, all evaluators felt that the inclusion of IWCD or their advocates in the evaluation design, in some way, was essential in their work.

Inclusion in the evaluation field. The last questions of each interview focused on the future direction of the evaluation field when it comes to including IWCD. The researcher asked the interviewees if they feel the topic of including IWCD in evaluations is relevant to the general evaluator who is not working in the disability field. All but one evaluator felt the topic is relevant for all evaluators. Some argued that inclusion is part of diversity, and just as it is important to be culturally competent and find ways to include individuals of all cultures, individuals of all abilities also need to be included. Other evaluators pointed out that individuals with disabilities, including cognitive disabilities, are in all sorts of programs and will eventually be in most evaluators' target populations. For example,

> Yes, absolutely. Because they're running into people with disabilities, and they're running into people with cognitive disabilities in any kind of research they're doing. And generally, I think those people get excluded. (Participant 2)

Another evaluator pointed out that as many evaluations have federal funding, the evaluators really need to know how to make an evaluation accessible to comply with the Americans with Disabilities Act. Evaluators noted that by using universal design, evaluators can make their projects accessible to everyone, not just IWCD, and that such changes would benefit many including those with limited English proficiency, illiteracy, and physical disabilities.

One evaluator felt that the issue of inclusion of IWCD was less relevant for evaluators outside the disability field, arguing that first the evaluators in the disability field need to do a better job. That participant said,

> At this point, I think it's less relevant. I mean, I think it's -- at this point in the evolution of evaluation, I think it's more important for evaluators that are working

> in the field of disability to have a pretty good understanding. And I'm not sure that that's the case. (Participant 1)

All of the participants agreed that evaluators should increase the number of IWCD who are included in evaluations. Some commented on how far the evaluation field has come already in paying more attention to diversity and inclusion. Increased inclusion was seen as important both to reduce the marginalization of the group, and to improve the validity of the evaluations. One evaluator commented,

> I think it's dependent on the kind of evaluation. But what I do worry about with the evaluations that are looking at a broad cross-section of individuals, that if they don't accommodate people with those kinds of needs, then they're going to exclude them, and that's going to bias the results. So I think, from that perspective, it's important. (Participant 11)

The participants were less clear about how to increase the inclusion of IWCD in evaluations. Many participants struggled to answer this question, but overall several suggestions were provided. One evaluator suggested that there needs to be a better system in place to identify IWCD who want to participate in evaluations, especially large scale evaluations at the state or federal level, such as a participant registry. Another way to increase inclusion in evaluations is to increase inclusion in the actual programs. Participants also mentioned determining if there is a response bias issue, in that IWCD are less likely to respond to requests for participation than other groups. One evaluator suggested that evaluators look at response bias from a socioeconomic perspective. Many IWCD are low income and may not have cell-phones, computers, or easy transportation, all of which can reduce participation.

Some evaluators suggested increasing inclusion by addressing issues within the evaluation field itself. These evaluators felt that evaluators tend to think that individuals with disabilities are a small group and that the disability field will take care of their needs. One evaluator felt that AEA members have little interest in this population, as demonstrated by the low attendance at the DOVP TIG sessions at the annual AEA conferences.

When asked about better educating evaluators to work with IWCD, participants discussed the need for more discussion about the inclusion of individuals with disabilities at AEA, aside from the TIG. One evaluator noted that the disability field and the DOVP TIG at AEA need to be more inclusive themselves and welcoming to AEA members who are new to working with IWCD. Although not specifically about AEA, one evaluator shared,

> Okay, number one, don't beat people up for not using person-first language. Oh, my gosh. I was -- I was publicly humiliated and massacred for not using person-first language. And I think we just need to be gentle with those who are totally unfamiliar with that. Because, you know, that's -- that was enough to make me think, okay, you know, this group of people that I have the -- that I may be working with, they're a bunch of assholes. I don't want to work with them at all. (Participant 5)

Several evaluators suggested that the DOVP TIG do more outreach to other members at AEA through co-sponsoring sessions with other TIGs at the annual conference and by sharing tips in the AEA365 emails. Written materials on universal design and ways to adapt methods when working with IWCD and IWD overall should be shared and made available online. One evaluator noted that the more materials are shared, the more inclusive evaluation will be “legitimized” in the field. Evaluators noted that when they looked for guidance on how to include IWCD in evaluations, they had difficulty finding resources, particularly resources focusing on evaluation rather than research. A few participants were unaware of the TIG or if they do any sessions at AEA, and others would like more sessions on disability issues.

A few evaluators approached this question from a longer-term perspective, focusing on the education of evaluators. One interviewee recommended that more IWCD be brought into the evaluation field so that there are more self-advocates making their presence known. Another evaluator suggested that education programs focus more on diversity and ethics, stating,

> I think evaluation somewhat, you know, pulls in technically oriented people who then learn more about the philosophical framework. And putting that on the front end of our educational programs, I think, would be – strengthening that on the front end. Because I think a lot of places have done so. And then looking at how methods courses can be sort of almost a contingency approach to methods from the standpoint of making them more responsive and inclusive. (Participant 8)

Finally, a few evaluators mentioned that studies like this dissertation project were bringing these issues to evaluators' attention.

Chapter 5: Discussion

This chapter discusses the study's results in relation to the research questions. The research questions were:

Question 1: What is the nature and degree of the participation of individuals with cognitive disabilities in evaluation?

Question 2: To what extent do evaluators consider individuals with cognitive disabilities when planning evaluations?

Question 3: Why do evaluators choose to include or not include individuals with cognitive disabilities in the evaluation process?

The first section examines how the survey and interview results compare in this mixed-methods study. The second section reexamines the literature based on the research results. The third section provides suggestions for future research, and the final section discusses recommendations for changes in the evaluation field based on the research findings.

Cross-Method Analysis

The benefits of conducting mixed-methods studies are that the multiple methods can be complimentary and provide for a broader understanding of the topic (Bazeley, 2009; Creswell & Plano-Clark, 2010). In this study, the survey was designed to examine if and how evaluators with a broad range of experiences were including IWCD in their evaluation studies. The interviews then explored in depth the experiences of evaluators who had conducted multiple evaluations with IWCD, as well as their perspectives on the evaluation field's practices. The interviewees are essentially the experts in this area. In relation to the research questions, both methods contribute to our understanding of each question.

In response to Question 1, the survey data show that majority of evaluators feel their evaluations that included IWCD were of equal or higher quality than other projects. Responses to the open-ended survey questions as well as the interviewee responses suggested that evaluations that include all voices, including IWCD, are of higher quality than when this group is not represented. Further, evaluators suggested that the direct participation of IWCD, rather than by proxy, is ideal for increasing evaluation quality. Furthermore, the interviewees emphasized the importance of including IWCD in the design of the evaluation, usually as consultants on advisory boards. Yet most survey participants, particularly in the general and culture groups but also in the disability group had never included IWCD in this way. Although it is possible that some survey participants did not consider participation on an advisory board as inclusion as a consultant or team member, this is unlikely the case for the vast majority of respondents who answered no, and no participants mentioned confusion with that question elsewhere in the survey.

The types of methods used to collect data from IWCD are the same as the common methods used in most evaluations: interviews, focus groups, surveys, psychometric testing, and the use of previously compiled data sets. Survey participants were not given the opportunity to list additional methods they may have used, but the interviewees did not describe the use of other methods. The interviewees did mention a number of accommodations they have made to their methods, such as simplifying language, using proxies when necessary, and conducting data collection one-on-one. Although they sometimes used different data collection techniques for different individuals, they did not feel this reduced the quality of the evaluations, but rather increased the validity. Some survey participants expressed concern that altering methods for some individuals would reduce the validity of the evaluation, particularly when using standardized measures. The interviewees were not particularly concerned with this prospect, arguing that in evaluation you must do the best you can based on the circumstances.

Based on the comments, it appears that some evaluators who responded to the survey appear to use more experimental designs than do the interview participants. The different evaluation approaches used by evaluators may influence the degree to which the perceived validity of an evaluation is impacted by the inclusion of IWCD. The interview participants heavily favored participatory approaches to evaluation, although the survey showed that the majority of evaluators, across all groups, do not always conduct their evaluations using a participatory approach.

The second research question asks the extent to which evaluators consider including IWCD in evaluations. The survey shows that evaluators with a focus on disability are likely to include or consider including IWCD. Among the general and culture group participants that had never included IWCD directly in their evaluations, the vast majority had also not considered their inclusion either as participants or as consultants or members of the evaluation teams. These findings are not surprising considering that several interviewees mentioned that they do not always include IWCD when they are conducting evaluations outside the disability field. The interviewees, however, mentioned that they felt more aware of the population and likely to include those individuals than they would have they not been working in the disability field. These responses mirror the survey results, which show that those in the DOVP TIG are more likely to include IWCD than the general and culture groups. Participants in both study components noted that there are situations in which the issue of inclusion is irrelevant because no such individuals are served by the program being studied. Most participants agreed that accommodations should be made whenever necessary, and yet the survey clearly shows that often accommodations are not made.

The third research question delves into why the levels of inclusion are not higher. Although Question 3 focuses on the intentional choice that evaluators make around whether or not to include IWCD, evaluators must first be conscious of the existence of the need for such a choice. While the majority of the General and Culture groups felt that most of the programs they evaluate do not serve some IWCD, the majority also felt they could not identify if there were IWCD in those programs. As some of the interviewees explained, cognitive disabilities are often hidden disabilities, and if individuals choose not to disclose their disabilities, evaluators may not be aware of their presence in the program. Evaluators who have worked with IWCD before may be more likely to look for this subgroup in a program and then decide if and how to include them in the evaluation.

Ethical concerns also appear to influence evaluators’ decision making around inclusive evaluation. Many of the surveyed evaluators mentioned issues around consent and IRB as potential challenges of inclusion. Participants from both methods mentioned that the IRB process could take longer and be more extensive. However, the interviewees demonstrated that the level review from IRBs varies by institution just as it does for any other type of evaluation. Some evaluations with IWCD were considered exempt; other IRBs considered IWCD a vulnerable population that required full review. Generally, the interviewees were able to come to an agreement with the IRB in terms of the necessary accommodations needed during the consent process. One of the interviewees also experienced this obstacle when wanting to include IWCD on the evaluation team.

The ability to make accommodations in the evaluation design and methods is another factor in an evaluator's decision to include IWCD. The majority of general and culture evaluators did not know of ways to modify data collection methods. Many of these participants mentioned concerns about how to make accommodations when asked about potential challenges. The interviewees were experienced in modifying methods and, although they agreed it was a challenge at times, did not feel that the need for modifications was a reason to exclude IWCD. The interviewees did state that they are less certain of whether to include IWCD when the program does not focus on disability and the number of IWCD is small. This consideration is primarily based on feasibility as accommodations generally take extra time and money. Participants were not sure funders would be willing to support the extra effort if IWCD were not a population of concern to them. Similar issues were mentioned by the interviewees regarding involving IWCD in the evaluation design process. The additional meetings and modifications to materials can become costly.

In addition, the survey showed that many evaluators do not feel comfortable collecting data from IWCD. The interviewees discussed the importance of having experience in the disability field and working with IWCD to effectively communicate with IWCD. In some cases the evaluators were training IWCD to collect the data to increase the comfort of participants and thus the validity of the study. Many of the survey participants had worked in the disability field at some point in their lives or had a close family member with a cognitive disability.

The many challenges of including IWCD in evaluations must be weighed against the potential benefits. Evaluators across methods agreed that there are many benefits to including IWCD such as a unique perspective, giving a marginalized group a voice in the programs in which they participate, and increasing the validity of the evaluations. The interviewees explained that whenever possible, it is important to hear directly from IWCD, as proxies can distort the data with their own biases. In addition, including IWCD in the evaluation design helps ensure that the design provides the necessary accommodations and is culturally competent to different groups. Certainly balancing the benefits with the additional costs is easier for the evaluators who have had experience working with IWCD in evaluations.

Comparison to Existing Literature

Many of the themes from the literature that are discussed in Chapter 2 surfaced in the results of this study. Although there are some concerns in the literature about the potential harm to participants with cognitive disabilities (Hubbard et al., 2003) and a long history of abuses in research, the interviewees were not particularly concerned that participants were being harmed through their participation in the evaluations. Participants struggled to think of any ways that the participants might be harmed and noted that IRB review ensures the protection of the participants. Evaluators who work without IRB approval may be more likely to share the concerns. The literature suggests that IRBs may be overly restrictive, preventing the inclusion of IWCD (Iacono & Carling-Jenkins, 2012). The interviewees generally did not find IRBs to be unreasonable, although some mentioned needing to go back and forth repeatedly to further educate and compromise with the IRB. One evaluator also struggled with the need for human subjects training for all staff working on the project.

The literature emphasizes the importance of ensuring that all participants understand the consent process by making sure the information is accessible to IWCD (Sherratt et al. 2007; Andre-Barron et al., 2008; The Alzheimer's Association, 2004). Whether nor IRB approval was required, the interviewees shared this appreciation for the importance of making consent accessible. The participants described several creative ways, including the use of videos and comic books, to help participants understand the consent process. Much of the research literature discussed consent for individuals with severe disabilities and the need for surrogate consent and advanced directives (Black et al., 2010; Slaughter et al., 2007; Yarborough, 2002). These topics were not raised in the interviews, and most participants did not include individuals with severe disabilities in their evaluations. It is unclear whether or not the inclusion of IWCD when surrogate consent is required has not been done in the evaluation field or if those evaluators just were not included in this study.

Much of the literature and the discussion in interviews focused on data collection. The interviewees seemed to be well versed in the common ways to make methods accessible, suggesting that much of the literature around researcher with IWCD is indeed relevant to evaluation practice. Researchers have found that basic modifications to instruments, such as the use of large, clear fonts and simplified language, are helpful for IWCD (Dalemans et al., 2009; Finlay & Lyons, 2001). These techniques were also mentioned by the interview participants. Participants also discussed the challenge of acquiescence. However, compared to the literature, the interviewees were limited in their descriptions of accommodations made. Some of the techniques discussed in the literature that were mostly or totally absent from the interviews include conducting interviews over multiple sessions, offering words, using gestures, having participants review the contributions at a later time, and using shorter scales (Carlsson et al., 2007; Finlay & Lyons, 2001; Hubbard et al., 2003; Lloyd et al., 2006). These differences may be due to the fact that the researchers were collecting data from individuals with more severe disabilities than the study participants, or it is possible that many of the techniques that are used in research have not yet made it over to evaluation practice. Likewise, while there is much in the literature about recruitment challenges and strategies (see Cleaver et al., 2010; Swaine et al., 2011), only one evaluator mentioned difficulties with recruitment. The absence of difficulty may be in part because program staff often provide evaluators with a means of recruiting.

The interviewees shared similar views toward the use of proxies as are present in the literature. The use of proxies can result in less reliable data, but this is better than no participation at all (Cusick et al., 2000). The participants agreed with Claes et al. (2012) and others that whenever possible, the data should be collected directly from the participant even if a support person needs to be there to assist. As noted by Claes et al. and Cusick et al., proxies do not always provide accurate responses, particularly for subject measures. This challenge was echoed by a few of the interviewees. The evaluators did not discuss many situations in which care givers in the room influenced the participants' responses.

In discussing the inclusion of IWCD on the evaluation team, the interviewees generally agreed with Johnson (2009) that inclusion requires a participatory approach. All of the interviewees used what they described as participatory approaches in their evaluations, although most did not go so far as to describe their work as emancipatory with the ICWD controlling the study (Boland et al., 2008). As with Bigby and Frawley (2010) who realized they could not fully train the IWCD in research methods for one study, the interviewees discussed doing some basic evaluation training for these individuals and asking them to contribute their knowledge of their cultures, community, and abilities to help strengthen the evaluation and make the process accessible to the population.

Finally, the evaluation literature on cultural competence often includes IWD as a group that needs to be included in evaluations (AEA, 2011; Yarbrough et al., 2011). Because consideration for making evaluations accessible to individuals from different cultures is a focus of cultural competence, the researcher theorized that individuals who are particularly focused on cultural differences would also be more inclusive with IWCD.

This was not the case. The culture group showed few differences from the general group on the survey results. Many participants, however, mentioned the importance of diversity in evaluations under the benefits of inclusive practice. The bulk of literature on inclusive research and evaluation practices comes from the disability field journals rather than the methods journals. Likewise, most of the evaluators who have experience conducting evaluations with IWCD come from the disability field. Unlike cultural competence, inclusive evaluation has not yet assimilated into mainstream evaluation practice, so the majority of evaluators are not cognizant of the need or importance of inclusive practices.

Recommendations for Future Research

This dissertation study attempted to cover a range of perspectives and topics, but there are many areas in which additional research would be beneficial. First, the study focused solely on members of the AEA and UCEDD staff. There are many evaluators who are not part of these institutions who work both within and without of the disability field. These may be evaluators with less of an academic interest in evaluation but who still regularly conduct evaluation projects. Understanding those evaluators’ knowledge and practice around including IWCD would help us to better see the degree of practice. Further, although the survey included some international participants, this study focused primarily on practice within the United States. Acceptance and accommodations of disabilities vary by country and by culture. An examination of cultural and geographic differences in practice would be valuable and may provide new insights into inclusion in the United States.

Several studies have explored the impact of modifications and accommodations to methods used in research. Little research has looked at methods specifically in the evaluation field. While this study has examined which modifications evaluators report using often, further examination of how those modifications impact validity would answer many evaluators' questions about the potential negative impact of altering methods for IWCD.

Finally, the biggest deficit of this study is the missing voice of IWCD. Sadly, as with many of the evaluations described in this study, the researcher did not have the capacity to intentionally include IWCD who have been participants in research or actively worked on evaluation teams. Their input would be most valuable in understanding the impact of both inclusive and exclusive evaluations, and suggestions for improving practice. Additional research should be conducted together with IWCD to explore inclusive evaluation from their perspective.

Recommendations for the Evaluation Field

The results from the surveys, interviews, and literature review conducted for this dissertation study together suggest several recommendations of how the evaluation field can increase the use of inclusive practice. Evaluators need to focus more on education and sharing resources such as methods of accommodations for consent and data collection, how to work with IRBs, and strategies for including IWCD in the evaluation design process. The survey revealed that most evaluators do not feel they have the methods or skills needed to conduct inclusive evaluations. The interview participants have many of the necessary skills, but still do not utilize many of the strategies suggested in the literature. Furthermore, the literature comes primarily from the disability and clinical fields. Evaluators need a central depository of literature citations and other resources available on including IWCD or even IWD overall. The DOVP TIG would be the ideal group to facilitate the development of such a resource through their website. Evaluators can be educated through the DOVP TIG sessions and the annual AEA conference, but the interviews revealed that not everyone is aware of the TIG or if they have sessions at the conference, and the attendance at those sessions tends to be low. The TIG needs to find ways to reach out to other evaluators, which leads to another recommendation: AEA needs to sponsor the need for more inclusive evaluations.

This study has revealed that many evaluators do not feel that inclusive evaluation practice is relevant to their work, that evaluators may not be aware of the presence of IWCD in the programs they evaluate, and that they do not have the knowledge to include IWCD or feel comfortable doing so. The inclusion of IWCD and individuals with all types of disabilities in program evaluations is an ethical imperative that is backed by the ADA. As this population continues to grow and become more active in society, such a lack of awareness by evaluators will become more detrimental both to the evaluators and to IWCD.

Due to limited time and resources, it is unreasonable to expect that every evaluator make every evaluation accessible to all program participants with all types of disabilities, particularly if those individuals are not major stakeholders in the program. However, evaluations should not be limited in their inclusion by ignorance or a lack of awareness of IWCD. To ignore the presence of IWCD and their accommodation needs is to continue the marginalization of a group that wants to and needs to be heard. To be an inclusive field, all evaluators should have enough recognition of the issue to consider whether or not they need to provide accommodations in their projects. To ensure consideration, evaluators would benefit from a habit of following a decision process of questioning if there is a need for inclusion, and if it can be addressed, as demonstrated in Figure 6. Evaluators should then have sufficient knowledge of available resources to provide the accommodations they identified, whether that be through examples of accommodations or the use of consultants who specialize in working with IWCD. Evaluators should also become familiar with the principles of universal design, so that their evaluations are always accessible to individuals of multiple abilities, whether they are aware of their presence in the program or not.

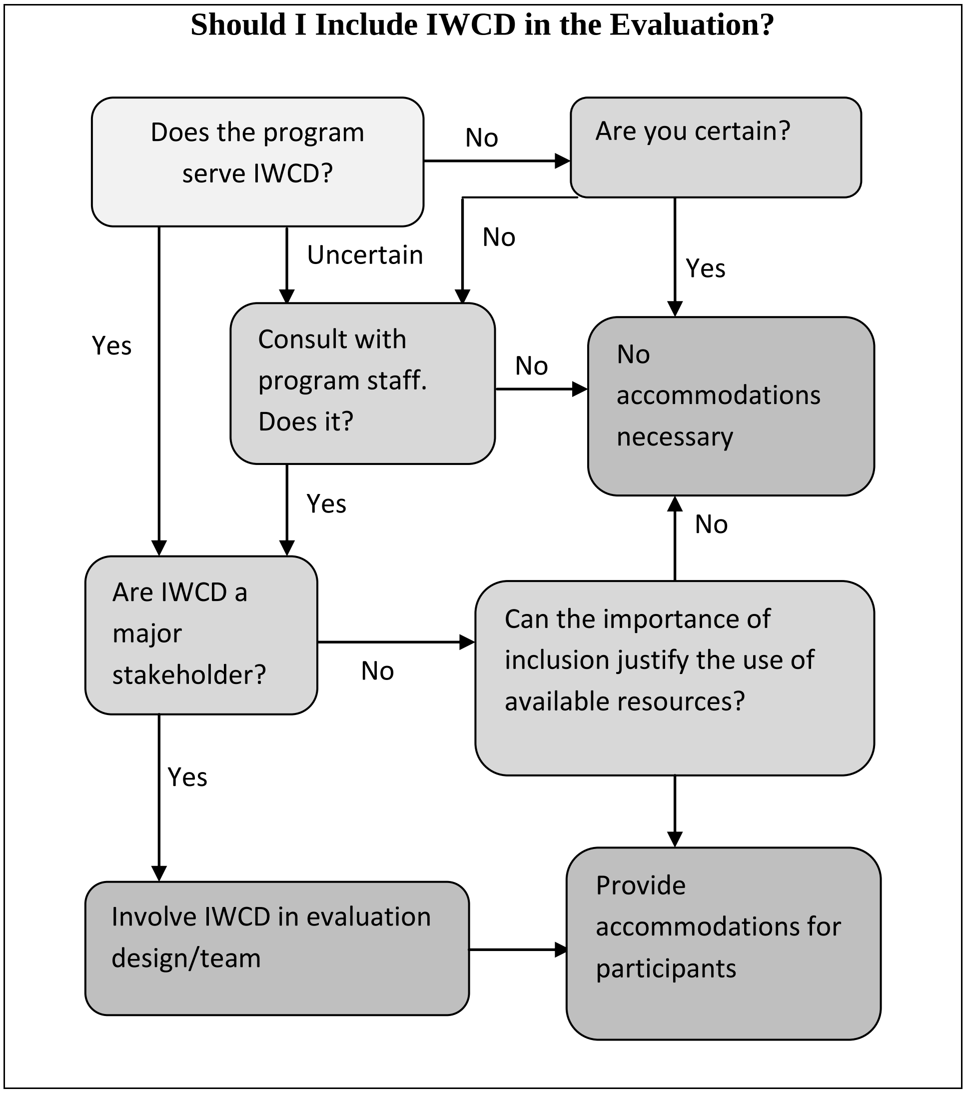


Figure 6. Recommended thought process for considering inclusive evaluation practice.

The AEA has done an excellent job in their promotion and encouragement of the use of culturally competent practices: multiple conference themes have been focused on the topic of culture and diversity, and the association released a statement emphasizing the importance of cultural competence in evaluation. Although disability is included as a category in that statement and certainly there are many disability cultures, the need for accommodations and universal design practices is distinct from cultural competence. Inclusive evaluation means making the evaluation process as accessible to IWCD as it is to other stakeholders. Cultural differences are often visible to evaluators, but cognitive disabilities are often hidden. Evaluators need to be more aware that diversity includes more cultural and racial differences. Inclusive evaluation involves unique challenges such as the use of proxies, surrogates, guardians for adults, and communication difficulties that go beyond language and cultural differences. If the AEA decided to emphasize the importance of inclusive evaluation and the use of universal design, it would move the discussion out of one of the smallest TIGs in the association and into the mainstream evaluation world.

All federally funded programs are required to abide by the Americans with Disabilities Act, which requires that programs and their evaluators make all aspects of a program accessible to all abilities. AEA needs to push federal funders to enforce this requirement by emphasizing both the validity and ethical benefits of inclusion and using universal design in evaluations. Major funding organizations should develop policies to ensure that evaluations are including the voices of the underrepresented population of IWCD. Once funders begin to mandate the use of inclusive evaluation designs, as they are beginning to with culturally competent designs, evaluators will have no choice but to become better educated about how to be inclusive and to seek out appropriate resources. Beginning at the policy level will likely create a trickle-down effect in which subcontractors and states with federal money are required to follow suit, and other funding organizations choose to follow federal guidelines to ensure their work is viewed as reputable. Thus, AEA can help increase inclusive practice by starting at the bottom through better educating evaluators about the importance of inclusion, and from the top by helping to push forward policies that ensure ADA is being enforced in the evaluation field.

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Appendix A – AEA Survey

Evaluation and Cognitive Disabilities

Survey Description: This study is part of a Doctoral thesis project that will examine the amount and types of experiences evaluators have working with individuals with cognitive disabilities. The purpose is to determine to what extent evaluators are including individuals with cognitive disabilities in evaluation studies and why. The information collected from this survey will contribute to the field's knowledge of inclusion issues in evaluation and will help identify areas for future research.

The questions in this survey ask about your experiences as an evaluator and your experiences with individuals with cognitive disabilities. Cognitive disabilities are disabilities that include an impaired ability to think, often presented through difficulties with remembering, conceptualizing, concentrating, making decisions, planning, organizing, and self-expression. Examples of cognitive disabilities include intellectual disabilities such as Down syndrome and autism, Alzheimer's Disease, brain injury, and aphasia. You do not need to be knowledgeable about specific cognitive disabilities to complete this survey. At the end of the survey there is space for you to provide any additional details that you feel are important or to expand on any of your responses. The survey will take about 5-10 minutes to complete.

Procedures: If you agree to be in this study, we would ask you to do the following things: Complete a 5-10~ minute survey. At the end of the survey you may be asked if you would be willing to participate in one 60~ minute interview. If you are willing, there is space to leave your contact information. Your contact information will not be stored with the survey data. Instead, an identifier will be used to link your survey and interview responses. Details about confidentiality and consent will be reviewed again at the time of the interview.

Risks and Benefits of being in the Study: The study has two risks: First, reflecting on your professional experience and challenges may bring up some negative emotions. Also, discussing issues about disability may create some discomfort.

The benefits to participation are: Participating in this study will allow you to reflect on your experiences in evaluation and may help you identify strategies that have been helpful to you in your work.

Compensation: No compensation will be provided for participating in the survey. A $10 gift card to Amazon or Target will be provided to interview participants.

Confidentiality: The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research records will be stored securely and only the researcher will have access to the records. If you agree, I would like to record the interview. To maintain confidentiality, you will not be asked to state your name on the recording. You may request that I stop the recorder at any time.

Voluntary Nature of the Study: Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota.

If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions: The researcher conducting this study is: Amelia Maynard, Doctoral Candidate in Evaluation Studies. You may ask any questions you have now. If you have questions later, you are encouraged to contact her at 612-356-4355, mayn0065@umn.edu. You may also contact her doctoral advisor, Jean King, at kingx004@umn.edu or 612-626-1614.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher(s), you are encouraged to contact the Research Subjects' Advocate Line, D528 Mayo, 420 Delaware St. Southeast, Minneapolis, Minnesota 55455; (612) 625-1650. If you agree to participate in this study, please continue to the survey.

Thank you!

Directions: For each question, please check the option that you feel best describes your experience as an evaluator. Cognitive disabilities are disabilities that include an impaired ability to think, often presented through difficulties with remembering, conceptualizing, concentrating, making decisions, planning, organizing, and self-expression. Examples of cognitive disabilities include intellectual disabilities such as Down syndrome and autism, Alzheimer's Disease, brain injury, and aphasia.

Q1 Have you ever worked in the disability field in any way?

- ○ Yes (please describe) ____________________
- ○ No

Q2 How many evaluations have you worked on with programs that are designed to serve primarily individuals with cognitive disabilities?

- ○ None
- ○ 1 - 2
- ○ 3 - 4
- ○ 5 or more

Q3 In any evaluation projects that you have worked on, have you ever made accommodations for participants with cognitive disabilities?

- ○ Yes
- ○ No

Q4 How many times, if ever, have individuals with cognitive disabilities been purposefully included in your evaluation projects in these ways?

	Never	1 - 2 times	3 - 4 times	5 or more times
As individuals included in previously compiled public data sets (for example, test scores or census data)	○	○	○	○
As individuals included in data that someone else collected for the evaluation	○	○	○	○
As participants from whom you collected data directly	○	○	○	○
As consultants for the evaluation team	○	○	○	○
As full members of the evaluation team	○	○	○	○
As the principal investigator of the evaluation	○	○	○	○

Q5 To what extent do you agree or disagree with these statements?

	Strongly Agree	Agree	Disagree	Strongly Disagree
Most programs I evaluate serve some individuals with cognitive disabilities.	○	○	○	○
I can usually determine if there are individuals with cognitive disabilities in programs that I evaluate.	○	○	○	○
I know ways to modify data collection methods for individuals with cognitive disabilities.	○	○	○	○
I feel comfortable collecting data directly from individuals with cognitive disabilities.	○	○	○	○
Most evaluation funders would be willing to provide resources to facilitate collecting data from individuals with cognitive disabilities.	○	○	○	○
Evaluators should always make the necessary accommodations for an individual with a cognitive disability to participate.	○	○	○	○

Q6 Thinking across all of the evaluations you have conducted, how often do you use these evaluation approaches?

	Always	Frequently	Occasionally	Never	Unsure
Culturally competent	○	○	○	○	○
Transformative	○	○	○	○	○
Participatory	○	○	○	○	○
Formative	○	○	○	○	○
Summative	○	○	○	○	○

Q7 Have you ever considered including individuals with cognitive disabilities in your evaluations? Select all that apply.

- ☐ Yes, as participants
- ☐ Yes, as a consultant
- ☐ Yes, as a member of the evaluation team
- ☐ No

Q8 Overall, how would you rate your experience of including individuals with cognitive disabilities in your evaluations?

- ○ Very positive
- ○ Somewhat positive
- ○ Somewhat negative
- ○ Very negative

Q9 Overall, how would you rate the quality of your evaluation(s) that included individuals with cognitive disabilities compared to other evaluations you have conducted?

- ○ Higher quality
- ○ Equal quality
- ○ Lower quality
- ○ Unsure

Q10 Have you personally used each of these data collection methods with individuals with cognitive disabilities as participants?

	Yes	No
Individual interviews	○	○
Group interviews	○	○
Focus groups	○	○
Observations	○	○
Questionnaires	○	○
Psychometric testing	○	○

Q11 What do you feel are the benefits of including individuals with cognitive disabilities in evaluations?

Q12 What do you feel are the challenges to including individuals with cognitive disabilities in evaluations?

Q13 How many years have you worked as a program evaluator?

- ○ 0 - 4 years
- ○ 5 - 9 years
- ○ 10 - 14 years
- ○ 15 or more years

Q14 Have you evaluated these types of programs in the last 5 years?

	Yes	No
Education	○	○
Nonprofit	○	○
Social Service (government run)	○	○
Health care	○	○

Q15 Do you currently practice evaluation in these settings?

	Yes	No
In a post-secondary academic institution	○	○
In a preK-12 education institution	○	○
In a nonacademic government agency	○	○
In a nonacademic non-profit organization	○	○
In a for-profit organization	○	○
As an independent contractor	○	○

Q16 What is the highest level of education that you have completed?
- ○ Some high school
- ○ High school
- ○ Associate's/Technical degree
- ○ Bachelor's degree
- ○ Master's degree
- ○ Doctoral degree

Q17 What is your gender?
- ○ Female
- ○ Male
- ○ Other
- ○ Prefer not to say

Q18 Have you ever been a member of the American Evaluation Association's Topical Interest Group on Disability?
- ○ Yes, currently a member
- ○ Yes, but no longer a member
- ○ No, have never been a member
- ○ Don't know

Q19 How would you best characterize yourself professionally?

- ○ Primarily an evaluator
- ○ Primarily a researcher
- ○ Equally a researcher and evaluator
- ○ Other

Q20 Is there anything else you would like to share about yourself or your experience working with individuals with cognitive disabilities?

Q22 Would you be willing to participate in an interview on this topic? Most interviews will be conducted over the phone and will take about an hour. Selected interview participants will receive a $10 gift card to Amazon or Target as a thank you. If yes, please enter your preferred contact email.

- ○ Yes (please enter email) ____________________
- ○ No

Appendix B – UCEDD Survey

Evaluation and Cognitive Disabilities

Survey Description: This study is part of a Doctoral thesis project that will examine the amount and types of experiences evaluators have working with individuals with cognitive disabilities. The purpose is to determine to what extent evaluators are including individuals with cognitive disabilities in evaluation studies and why. The information collected from this survey will contribute to the field's knowledge of inclusion issues in evaluation and will help identify areas for future research.

The questions in this survey ask about your experiences as an evaluator and your experiences with individuals with cognitive disabilities. Cognitive disabilities are disabilities that include an impaired ability to think, often presented through difficulties with remembering, conceptualizing, concentrating, making decisions, planning, organizing, and self-expression. Examples of cognitive disabilities include intellectual disabilities such as Down syndrome and autism, Alzheimer's Disease, brain injury, and aphasia. You do not need to be knowledgeable about specific cognitive disabilities to complete this survey. At the end of the survey there is space for you to provide any additional details that you feel are important or to expand on any of your responses. The survey will take about 5-10 minutes to complete.

Procedures: If you agree to be in this study, we would ask you to do the following things: Complete a 5-10~ minute survey. At the end of the survey you may be asked if you would be willing to participate in one 60~ minute interview. If you are willing, there is space to leave your contact information. Your contact information will not be stored with the survey data. Instead, an identifier will be used to link your survey and interview responses. Details about confidentiality and consent will be reviewed again at the time of the interview.

Confidentiality: The records of this study will be kept private. In any sort of report I might publish, I will not include any information that will make it possible to identify a subject. Research records will be stored securely and only the researcher will have access to the records. If you agree, I would like to record the interview. To maintain confidentiality, you will not be asked to state your name on the recording. You may request that I stop the recorder at any time.

Voluntary Nature of the Study: Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with the University of Minnesota. If you decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

Contacts and Questions: The researcher conducting this study is: Amelia Maynard, Doctoral Candidate in Evaluation Studies. You may ask any questions you have now. If you have questions later, you are encouraged to contact her at 612-356-4355, mayn0065@umn.edu. You may also contact David Johnson at johns006@umn.edu or 612-624-1062. If you agree to participate in this study, please continue to the survey. Thank you!

Directions: For each question, please check the option that you feel best describes your experience as an evaluator. Note: The questions you are being requested to respond to are also being asked of professional evaluators who are far less involved in working with individuals with cognitive disabilities. Some of the questions regarding how you involve individuals with cognitive disabilities may seem quite general, but the purpose is to be able to compare your responses with those of evaluators not necessarily involved in disability research and evaluation efforts.

How many evaluations have you worked on with programs that are designed to serve primarily individuals with cognitive disabilities?

○ None
○ 1 - 2
○ 3 - 4
○ 5 or more

In any evaluation projects that you have worked on, have you ever made accommodations for participants with cognitive disabilities?

○ Yes
○ No

How many times, if ever, have individuals with cognitive disabilities been purposefully included in your evaluation projects in these ways?

	Never	1 - 2 times	3 - 4 times	5 or more times
As individuals included in previously compiled public data sets (for example, test scores or census data)	○	○	○	○
As individuals included in data that someone else collected for the evaluation	○	○	○	○
As participants from whom you collected data directly	○	○	○	○
As consultants for the evaluation team	○	○	○	○
As full members of the evaluation team	○	○	○	○
As the principal investigator of the evaluation	○	○	○	○

To what extent do you agree or disagree with these statements?

	Strongly Agree	Agree	Disagree	Strongly Disagree
Most programs I evaluate serve some individuals with cognitive disabilities.	○	○	○	○
I can usually determine if there are individuals with cognitive disabilities in programs that I evaluate.	○	○	○	○
I know ways to modify data collection methods for individuals with cognitive disabilities.	○	○	○	○
I feel comfortable collecting data directly from individuals with cognitive disabilities.	○	○	○	○
Most evaluation funders would be willing to provide resources to facilitate collecting data from individuals with cognitive disabilities.	○	○	○	○
Evaluators should always make the necessary accommodations for an individuals with a cognitive disability to participate.	○	○	○	○

Thinking across all of the evaluations you have conducted, how often do you use these evaluation approaches?

	Always	Frequently	Occasionally	Never	Unsure
Culturally competent	○	○	○	○	○
Transformative	○	○	○	○	○
Participatory	○	○	○	○	○
Formative	○	○	○	○	○
Summative	○	○	○	○	○

Have you ever considered including individuals with cognitive disabilities in your evaluations? Select all that apply.

- ☐ Yes, as participants
- ☐ Yes, as a consultant
- ☐ Yes, as a member of the evaluation team
- ☐ No

Overall, how would you rate your experience of including individuals with cognitive disabilities in your evaluations?

- ○ Very positive
- ○ Somewhat positive
- ○ Somewhat negative
- ○ Very negative

Overall, how would you rate the quality of your evaluation(s) that included individuals with cognitive disabilities compared to other evaluations you have conducted?

- ○ Higher quality
- ○ Equal quality
- ○ Lower quality
- ○ Unsure

Have you personally used each of these data collection methods with individuals with cognitive disabilities as participants?

	Yes	No
Individual interviews	○	○
Group interviews	○	○
Focus groups	○	○
Observations	○	○
Questionnaires	○	○
Psychometric testing	○	○

What do you feel are the benefits of including individuals with cognitive disabilities in evaluations?

What do you feel are the challenges to including individuals with cognitive disabilities in evaluations?

How many years have you worked as a program evaluator?

- ○ 0 - 4 years
- ○ 5 - 9 years
- ○ 10 - 14 years
- ○ 15 or more years

Have you evaluated these types of programs in the last 5 years?

	Yes	No
Education	○	○
Nonprofit	○	○
Social Service (government run)	○	○
Health care	○	○

Do you currently practice evaluation in these settings?

	Yes	No
In a post-secondary academic institution	○	○
In a preK-12 education institution	○	○
In a nonacademic government agency	○	○
In a nonacademic non-profit organization	○	○
In a for-profit organization	○	○
As an independent contractor	○	○

What is the highest level of education that you have completed?

- ○ Some high school
- ○ High school
- ○ Associate's/Technical degree
- ○ Bachelor's degree
- ○ Master's degree
- ○ Doctoral degree

What is your gender?

- ○ Female
- ○ Male
- ○ Other
- ○ Prefer not to say

Have you ever been a member of the American Evaluation Association's Topical Interest Group on Disability?

- ○ Yes, currently a member
- ○ Yes, but no longer a member
- ○ No, have never been a member
- ○ Don't know

How would you best characterize yourself professionally?

- ○ Primarily an evaluator
- ○ Primarily a researcher
- ○ Equally a researcher and evaluator
- ○ Other

Is there anything else you would like to share about yourself or your experience working with individuals with disabilities?

Would you be willing to participate in an interview on this topic? Most interviews will be conducted over the phone and will take about an hour. Selected interview participants will receive a $10 gift card to Amazon or Target as a thank you. If yes, please enter your preferred contact email.

- ○ Yes (please specify email) ____________________
- ○ No

Appendix C – Interview Protocol

Background Questions:

"I would like to begin by briefly getting some background information about your experience in the evaluation field and in working with individuals with cognitive disabilities."

1. How long have you been conducting evaluations?
2. How did you become involved in working with IWCD?
3. What is your academic background (degree, major, if not obtained from survey)?
4. Approximately how many projects have you worked on that have included IWCD?
    a. Who did these programs serve (IWCD or general population)?
    b. What types of cognitive disabilities did the participants have? How would you describe the severity?
5. How would you define inclusive evaluation?

Main Questions:

"The next questions ask about your experience working with IWCD in evaluations. The questions will ask you to reflect on your experience overall and for any relevant examples that stand out from any project."

6. In what ways have you included IWCD in evaluations as participants?
    a. What do you feel were the positives or successes of those experiences?
    b. What were the negatives or challenges?
    c. In what ways, if any, did you accommodate the IWCD?

            i. Have you used proxies?
                1. Did you ever have any issues with using proxies?
            ii. Did you ever make different accommodations for different IWCD in one project?
    d. How did you decide to include IWCD as participants?
        i. Were the funders supportive?

7. In what ways have you included IWCD in evaluations as members of the research team?
    a. What do you feel were the positives or successes of those experiences?
    b. What were the negatives or challenges?
    c. In what ways, if any, did you accommodate the IWCD?
    d. How did you decide to include IWCD as participants?
        i. Where the funders supportive?
8. In what ways, if any, do you feel the IWCD benefited from their participation? Were they harmed in any way?
9. At what point in the evaluation do you generally decide if and how to include IWCD?
    a. How does the type of disability or severity affect your decision?
10. Have you ever intentionally decided not to include IWCD in an evaluation? How did you make your decision?
11. What obstacles, if any, have you encountered when trying to include IWCD?

12. [For those who conduct other types of evaluations] Do you ever include IWCD in the evaluations you conduct for programs that don't focus on IWCD? How do you decide?

13. Have you encountered any difficulties with IRBs?

14. Did you attempt to obtain consent from the IWCD? If so, how?

15. To what extent do you feel equipped to include IWCD in evaluations?

    a. As participants? Team members?

Concluding Questions

16. Do you feel this topic is relevant for the general evaluator? Why?

17. What do you feel would increase inclusion of IWCD in evaluations?

    a. How do you think evaluators can be better educated about including IWCD in evaluations?

18. What additional resources would help you to better include IWCD in evaluations?

19. Is there anything else you would like to share about your experiences working with IWCD?

Thank you.