

Learning From Vulnerable Populations: Methodological Implications of Interviewing Individuals With Fetal Alcohol Spectrum Disorder

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Abstract

Scholars face methodological challenges when conducting research about vulnerable populations, such as individuals living with fetal alcohol spectrum disorder (FASD). They often struggle to identify, sample, and interview individuals in order to learn about their life experiences and perspectives. Although some scholarship provides methodological guidance on researching vulnerable populations, scant literature addresses accessing and collecting perceptions from individuals with FASD. Based on work with adults with FASD, we offer procedures for sampling and interviewing. Our suggestions include working with agencies and gatekeepers involved with the population; ensuring voluntary and informed consent throughout the interview process; establishing rapport with interviewees and providing a comfortable interview environment for them; and adjusting interview questions according to individuals' cognitive abilities. By following these procedures, researchers can learn from these individuals while reducing the risk of harm to them.

Keywords

qualitative methodology, qualitative methods, interviewing, interviews, vulnerable populations, fetal alcohol spectrum disorder (FASD)

Introduction

Conducting research about vulnerable populations is a necessary, rewarding, yet challenging process. Vulnerable populations include individuals with intellectual, cognitive, or physical disabilities; children; elderly people; ethnic and racial minorities; and other people who might be prone to stigmatization or marginalization (Allen, 2002, p. 276). Research can enhance society's grasp on vulnerable individuals' lived experiences and perspectives, thus allowing for a better understanding of their needs and the interventions and resources that will best support them. To this end, researchers must discover optimal ways to learn from individuals while protecting them from harm to their health and well-being during the research process.

Based on coauthor Brenda Dow's (2019) research on the effects of fetal alcohol spectrum disorder (FASD) on the life quality of individuals and their family members,¹ this article addresses the methodological challenges associated with gaining access to and conducting interviews with individuals with FASD, as one class of vulnerable population, and offers suggestions on how to overcome these challenges.

FASD refers to the effects and disorders associated with maternal use of alcohol during pregnancy. Although other organs can be affected, the brain is the most sensitive to prenatal exposure to alcohol (Malbin, 2002). Prenatal alcohol exposure often leads to problems with executive functioning, including processing and remembering ideas and concepts, paying attention, determining cause and effect, and regulating emotions (Dow, 2019). The severity of alcohol's effects on the brain varies according to the amount of alcohol the mother consumes, when in the gestational development the mother consumes alcohol, whether the mother uses other drugs, the mother's genetic makeup, and nutritional factors. Owing to intellectual and cognitive impairments, individuals with FASD

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can be particularly vulnerable, thus researchers must establish additional protections for these individuals during the research process.

Although some literature on researching vulnerable populations exists, little research focuses on methodological strategies for working with and obtaining perspectives from adult individuals living with FASD. A 2018 review shows that individuals with FASD feel professional service providers do not have adequate knowledge of their needs (Domeij et al., 2018). Our article contributes to the small but important body of knowledge on effective strategies for conducting research with these individuals by sharing successful sampling and interviewing techniques. Our aim is to contribute to the literature on qualitative methodologies related to researching vulnerable populations such as individuals with FASD.

This article begins with a review of the literature on methodological considerations for vulnerable populations including individuals with intellectual disabilities. It then explains the sampling and interviewing methodology from Dow's (2019) research. It concludes with observations from the research process and suggestions on best practices and techniques. These include working with agencies that focus on vulnerable populations, ensuring voluntary and informed consent throughout the interview process, establishing rapport with and providing a comforting environment for interviewees, and adjusting interview questions according to individuals' intellectual abilities.

Researching Vulnerable Populations

Dempsey et al. (2016, p. 482) use the term "vulnerable" to describe sensitive or hard-to-reach populations who hold a social status that can minimize their autonomy and marginalize their lives. Given that individuals with FASD struggle with cognitive and behavioral difficulties that lead to mental health problems, difficulty living independently as adults, and even victimization (Streissguth et al., 1996), they fit this definition. Recognizing that vulnerable persons have an increased risk of incurring harm from the research process (Hurst, 2008, p. 191), researchers must take extra precautions to protect these individuals.

The concept of vulnerability in research became more visible in the United States with the release of the 1979 Belmont Report (Bracken-Roche et al., 2017). The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research wrote the report in response to ongoing concerns about ethics violations in research. The report specified policies and guidelines to protect vulnerable populations. The Commission also established institutional review boards (IRBs) to evaluate, authorize, and oversee research in an effort to protect subjects involved in the research process.

However, as a consequence, some researchers began to avoid pursuing research on vulnerable populations, owing to the real or perceived difficulty in gaining IRB authorization or to personal convictions that conducting this type of research might be unethical or damaging or "open old wounds"

(Alexander, 2010, p. 174). Other academics conducted research on vulnerable populations but did not solicit their perspectives (Coons & Watson, 2013). Instead, they relied on observations, medical records, and/or interviews with individuals who worked with vulnerable populations, ignoring the views of the affected persons.

Some argued that disregarding vulnerable populations was unethical, stressing that their involvement could provide a better understanding of their needs and perspectives and assist in the development of improved services (Alexander, 2010, p. 173; Beail & Williams, 2014). Others argued that research denying subjects' input was paternalistic and that researchers' confidence in their own expertise had led them to deny vulnerable individuals the right to autonomy and make their own decisions (Alexander, 2010; Hall, 2013). Individuals with disabilities, with support from disability researchers, developed the slogan, "Nothing about us without us" (Charlton, 2000, p. 3). As scholars started to recognize that individuals within any population group are the experts of their own life experiences, they advocated for finding the most appropriate approaches to understand their stories and perspectives without harming them in the process.

Concerns related to studying sensitive topics with vulnerable populations had also arisen. Sensitive topics include areas of human life that are stigmatizing or emotionally charged, such as deviant and illegal activities, serious health issues, or bereavement (Alexander et al., 2018). Researchers again determined that although studying sensitive topics with vulnerable populations presents challenges, it nevertheless can produce new knowledge and assist in the development of resources for these populations (Hall, 2013). Research groups developed national and international research ethics policies so that researchers would proceed with caution and develop appropriate techniques. For example, in 2002, the Council for International Organizations of Medical Sciences developed guidelines to assist researchers in the application of ethical principles to health research, which often involves sensitive topics such as diseases obtained through sexual contact and intravenous drug use (Bracken-Roche et al., 2017). Despite early concerns about traumatizing or retraumatizing participants, research shows that many vulnerable individuals have more recently felt that their involvement with research has been positive (Alexander et al., 2018; Biddle et al., 2013). Individuals appreciate the opportunity to advocate for themselves, feel heartened and encouraged, enjoy social interaction, and benefit from altruistic behavior (Alexander et al., 2018).

Conducting research on vulnerable populations, particularly those with intellectual disabilities, presents numerous challenges and requires care and caution. The term "intellectual disability" indicates that an individual has low intelligence; developmental, cognitive, or learning disabilities; or another mental handicap (Schalock et al., 2002). Individuals with FASD often have one or more of these conditions, which places them in this category.

FASD includes a wide range of more specific diagnoses. Fetal alcohol syndrome (FAS) is the most severe form of

FASD. Individuals with FAS have confirmed prenatal alcohol exposure; visible facial differences including small eyes, a smooth philtrum, and a thin upper lip; growth deficiencies, with heights and weights below the 10th percentile nationally; and severe cognitive and behavioral abnormalities. While the average IQ for individuals without FASD is 100, the average IQ for individuals with full FAS is 70, with a range between 20 and 130 (Malbin, 2002). Partial FAS (pFAS) is a less severe form of FAS. Individuals with pFAS do not meet the full diagnostic criteria for FAS but have the facial features consistent with full FAS. Individuals with static encephalopathy/alcohol exposed (SE/AE) have confirmed prenatal alcohol exposure, severe central nervous system damage, and significant functional abnormalities but not facial phenotypes (Astley, 2004). Individuals with neurobehavioral disorder/alcohol exposed (ND/AE) have confirmed prenatal alcohol exposure, moderate central nervous system abnormalities, moderate cognitive and behavioral abnormalities but not facial phenotypes. In 2013, the American Psychiatric Association updated this category to include a new diagnosis in the *Diagnostic and Statistical Manual, 5th edition (DSM-5)*—neurodevelopmental disorder associated with prenatal alcohol exposure (Kable et al., 2016). Before 2013, ND/AE was recognized as a condition but not a medical diagnosis. Sometimes, specialists on FASD diagnostic teams, neuropsychologists, and medical doctors apply the term fetal alcohol spectrum disorder (FASD) more generally to individuals with disabilities related to confirmed prenatal alcohol exposure who do not meet the criteria of a more specific diagnosis on the FASD spectrum.

Scholars face significant challenges pursuing research about individuals with intellectual disabilities such as accessing the population, ensuring voluntary and informed consent, and using appropriate techniques to elicit the information they need while providing the least stressful environment for interviewees.

One of the first challenges is accessing the population. Public lists of individuals with diagnoses or meeting research criteria do not exist; thus, academics must often use purposive and snowball sampling and respondent-driven techniques (Benoit et al., 2005; Faugier & Sargeant, 1997). One way researchers can access individuals fitting specific criteria is by partnering with community agencies with local knowledge about and relationships with members of the desired population (Anderson & Hatton, 2000). Researchers may also increase the reliability and validity of findings if they work with agencies over a long period of time and establish rapport and trust with their members. Such agencies may be able to provide collateral information to ensure that individuals meet the research criteria or provide additional information on the population (Benoit et al., 2005).² Networking with agencies and connecting with professionals may lead to contacts with members of the population (Faugier & Sargeant, 1997). Given that agencies and vulnerable individuals offer much to the research enterprise, researchers should reciprocate by providing research findings and suggestions on identifying resources (Quinn, 2015).

Although agencies may provide entry, gatekeepers can sometimes block access to individuals. Gatekeepers include

parents, caregivers, and other “parties with an interest in ensuring that ethical standards are upheld and with some degree of influence over the granting of access to the potential study population” (Walker & Read, 2011, p. 14). Gatekeepers are concerned that the research might harm the individuals about whom they care (Alexander et al., 2018; Ellard-Gray et al., 2015). Although some gatekeepers deny researchers’ access to individuals, they might inadvertently cause further marginalization by denying them the benefits they could receive from participating in research. Such resources include assistance with finding housing or employment and completing government agency forms. Interestingly, researchers have found that participants are generally more willing to participate than their caregivers or health care professionals would have expected (Alexander et al., 2018). When gatekeepers trust the research agenda and recognize potential benefits, they are usually more willing to provide access (Dempsey et al., 2016).

A second challenge is ensuring informed and voluntary consent throughout the interview process. Sometimes, vulnerable individuals do not understand the information provided to them in the informed consent form or their right to withdraw from the interview at any time. In addition to understanding the form, they should be able to discuss the research agenda, ask questions, and then decide if they want to participate in the research (Coons & Watson, 2013). To ensure that individuals comprehend the research goals and their rights, researchers may ask that they read the informed consent form and ask questions, review the informed consent together with the interviewees, or request that family members or caregivers help individuals understand the form. Nordentoft and Kappel (2011) concluded in their research on vulnerable participants that informed consent should be an ongoing process that is discussed and renegotiated during the entire research process. As one example, researchers should remind interviewees that they can decline to answer questions throughout the interview process or end the interview at any time.

A third challenge is determining the methodological approach to collecting data. Researchers often use interview methods when they want to understand the lived experiences and perspectives of the population in deep and meaningful ways. Interviews can capture the rich and in-depth description of respondents’ personal and collective perspectives (Bloomberg & Volpe, 2016). Although interviews with individuals with intellectual disabilities are often short in length, they still provide valuable information on individuals’ life experiences, including how their disability affects them (Beail & Williams, 2014). Developing a well-conceived interview protocol helps to provide a framework for collecting information (Brayda & Boyce, 2014). Before or after the interview, researchers can also share information on sources of support or care if the interviewee expresses the need.

Interview protocols can be structured, for standardization and comparison; semistructured, for standardization and flexibility; or unstructured, for conversational interviews and life narratives (Bracken-Roche et al., 2017). Researchers must identify the optimal interview format to not only elicit rich responses

but also put the interviewees at ease (Brayda & Boyce, 2014). Given that interviewers must often ask follow-up questions to interviewees with intellectual disabilities, requesting them to clarify or elaborate on their responses, and given that the structured interview does not allow for this type of questioning, scholars may not want to use this format. On the other hand, when researchers administer unstructured interviews, interviewees with intellectual disabilities often struggle in the conversation, owing to their difficulty with responding to open and broad questions and generalizing from their experiences (Beail & Williams, 2014). Thus, a semistructured format can be preferable. It allows researchers to ask premeditated and specific questions and follow up as necessary while permitting individuals to tell their stories on their own terms (Dempsey et al., 2016).

Face-to-face interviews are considered best practice for vulnerable populations (Dempsey et al., 2016). The interview location should be familiar and feel safe and private to interviewees (Anderson & Hatton, 2000; Hall, 2013). When starting the interview, researchers must establish rapport and create a comfortable environment (Brayda & Boyce, 2014). This not only puts interviewees at ease but also increases credibility by communicating that their information is important and valued (Marshall & Rossman, 1989). Researchers should use direct and ongoing observation to recognize how questions are affecting interviewees—especially important when working with individuals with cognitive disabilities, as they may struggle to express emotions. Interviewers should watch for body language and other clues that may indicate that interviewees do not understand questions, are uncomfortable with questions, or need to take pauses. Interviewers must devote adequate time to ensure that participants understand questions, using repetition and follow-up questions when necessary. Sometimes repeating interviewees' answers allows them to elaborate on their responses (Sigstad, 2014). Cultural sensitivity is also important (Brayda & Boyce, 2014), as cultural differences may make some questions more sensitive or taboo. Researchers should end interviews with positive closure and give interviewees the opportunity to provide feedback (Dempsey et al., 2016). Studies show that offering individuals a chance to share their stories can be therapeutic and help them feel valued, especially when they understand that their stories may be beneficial to others (Elmir et al., 2011; Nordentoft & Kappel, 2011).

Despite clear benefits, interview methodology does have some drawbacks. Research shows that individuals with cognitive disabilities struggle with understanding questions and formulating responses and have a tendency to acquiesce or respond "yes" when asked yes/no questions, regardless of the question (Coons & Watson, 2013; Sigstad, 2014). Researchers must account for these difficulties when developing interview strategies.

Methodological Approach

Sampling Procedure

Dow's study included 18 cases of individuals with FASD.³ For these cases, she interviewed eight individuals with FASD and 14 parents.⁴ She used a purposive approach to generate the

sample and attempted to increase the sample size through snowball sampling.⁵ All interviewees either had confirmed FASD or were parents, and all interviewees were 18 years or older.⁶

Interviewees came from three recruitment strategies: contacting families (1) associated with the Presbyterian Hospitality House (PHH), (2) associated with the Fairbanks Fetal Alcohol Community Evaluation & Services (FACES) Diagnostic Clinic, and (3) on the recommendation of colleagues at the University of Alaska Fairbanks (UAF). The IRB at UAF approved these recruitment strategies.

PHH offers a residential treatment program for teenagers who are severely emotionally disturbed. It also offers a therapeutic foster care program for children younger than 12, teenagers who do not need residential treatment, and individuals who have graduated from the residential program but are unable to return home for various reasons. PHH also has an independent living program for individuals aged 18–23 years who need assistance before they can live independently in the community.⁷ All children and young adults in PHH programs undergo a behavioral health assessment. The PHH Board of Directors approved Dow's research, and PHH staff provided the names of two foster parents of individuals with FASD whom they thought would be willing to participate in the research. Both parents agreed to the interviews. One of these parents arranged interviews with two foster sons, and with the consent of the young men, these interviews occurred at the PHH office. The other foster parent approached her former foster daughter about an interview, but she did not make contact for an interview. A third foster parent works at the PHH office and volunteered to do an interview once he heard about the research. He also arranged for an interview with a former foster daughter, with her permission, at the PHH office. Dow also contacted two other young adults with FASD once affiliated with PHH whom she knew. Both agreed to the interview. One interview took place at the PHH office, while another took place at Dow's home. Through PHH, Dow interviewed three parents and five adults with FASD.

Serving interior Alaska, the FACES Diagnostic Clinic facilitates the referral, screening, assessment, and diagnosis of legal minors, who experience difficulties owing to prenatal exposure to alcohol. In support of the research, the FACES Diagnostic Clinic Coordinator emailed all of the families that the diagnostic team supports, approximately 87 families, asking them to self-report if they would like to participate in the study.⁸ The coordinator's involvement in this recruitment effort was critical; she not only helped with logistics but also vouched for the credibility of the research and facilitated trust-building with interviewees (Rubin & Rubin, 1995). When the volunteers elected to participate, Dow arranged interviews according to their availability and with the assurance of confidentiality. This procedure led to interviews with eight parents. Of the eight parents, six had children under the age of 18. During interviews, two parents with adult children stated they would ask their children if they would attend the interview, and they agreed. All children had been diagnosed on the FASD spectrum

Table 1. Demographics of Research Participants.

Interviewee Number	Gender	Age	Ethnicity	Diagnosis
1	M	20	AN	FAS
2	F	30	AN	FAS
3	M	26	AN/AA	FAS/SCH
4	F	18	AN	ND/AE
5	M	22	W	SE/AE
6	M	19	AN	FASD
7	F	20	W	FASD
8	F	25	AN	FASD

Note. Ethnicity: AA = African American; AN = Alaska Native; W = White. Diagnosis: FASD = fetal alcohol spectrum disorder; FAS = fetal alcohol syndrome; ND/AE = neurodevelopmental disorder/alcohol exposed; SCH = schizophrenia; SE/AE = static encephalopathy/alcohol exposed.

by the FACES team. The mothers acted as intermediaries, helping to arrange the interviews. The two interviews took place in interviewees' apartments. One mother was not present, while the other attended the interview to help her child, who has schizophrenia in addition to FASD, feel more comfortable.

Finally, several of our colleagues at the UAF have friends or acquaintances who have adopted children with FASD. After our colleagues contacted their contacts for permission, they provided contact details so that Dow could arrange interviews. This process led to interviews with three parents; one parent also arranged an interview with her adult child.

Sample Characteristics

Dow's study evaluated 18 individuals, but this section focuses only on the interviews with the eight individuals with FASD.⁹ The interviewees ranged in the severity of FASD. Two individuals had a diagnosis of fetal alcohol syndrome (FAS), the most extreme form on the FASD spectrum. Another individual had both FAS and schizophrenia. One individual had SE/AE. One individual had ND/AE. Three others had FASD, generally. Interviewees also differed according to other demographics. Ages ranged from 18 to 30, with an average of 22.5. Four were men, and four were women. Ethnicity varied across interviewees: Five were Alaska Native, one was Alaska Native and African American, and two were White (see Table 1).

Designing the Interview Protocol

The primary data collection method was semistructured interviewing, a well-established approach to capture individuals' perspectives on a range of issues (Qu & Dumay, 2011). Interviews were structured with a set of questions asked of each interviewee while being flexible, so that interviewees could share their stories on their own terms. If interviewees did not answer questions on the interview protocol on their own, Dow asked the questions at the end of the interview. The process proved to be enlightening: Although interviewees' responses sometimes mirrored or complemented those of their parents or other adults, they often highlighted different concerns.

The interview protocol was developed using the key research questions and related literature (Fossey et al., 2002). Two bodies of work especially pertained: Verdugo et al. (2012) and Streissguth et al. (1996, 2004). Verdugo et al. (2012) developed a cross-cultural quality of life (QOL) framework to assist service providers and policy makers in addressing the needs of individuals with intellectual disabilities. Their framework focuses on the basic constructs of QOL: independence, social skills, and well-being. The independence component focuses on interviewees' daily living activities such as cooking and doing laundry, obtaining a driver's license, graduating from high school, and living independently. The social skills component concentrates on interviewees' ability to form and maintain friendships and perceived levels of social inclusion. The well-being component entails personal safety and security, health and nutrition, and employment. Moreover, Streissguth et al. (1996, 2004) also informed the interview guide. Streissguth and her colleagues have conducted extensive research on adverse life outcomes and secondary disabilities in individuals with FASD. Their work shows that individuals with FASD often have difficulty with adaptive behaviors. In the 2004 study, they found that 80% of the patients in their sample were not raised by their biological mothers, 61% had disrupted school experiences, 60% encountered trouble with the law, 50% experienced confinement in either detention or jail or a psychiatric or alcohol/drug inpatient setting, and 49% had exhibited inappropriate sexual behaviors. Dow added questions on these topics to the guide. In total, the protocol consisted of six categories of questions, including childhood, family and friends, employment, health, current struggles and difficulties, and the effects of FASD on life quality.

Conducting Interviews

According to the IRB protocol, researchers must use an informed consent form that relays to participants the purpose of the research and potential risks. Participants must read and sign the form before interviews can begin (Babbie, 2011). All interviewees signed the form and also agreed to audio recordings. Given that individuals with FASD are a vulnerable population, Dow spent additional time explaining the purpose of the research and the voluntary nature of interviews. Dow informed interviewees that they could choose to stop the interview at any time or skip any question. Informing interviewees of these rights minimized the likelihood of emotional or psychological risk. In two cases, a parent sat in to ensure that the interviewee understood the consent. Although no interviewee stopped the interview, some chose to skip questions.

The first interview also served as a pilot of the interview protocol. The interviewee provided feedback on the interview, read the transcript, and critiqued the questions. She felt the interview length and questions were appropriate and did not offer suggestions or additional questions. All interviews took place face-to-face, at a mutually agreed upon location. Interviews lasted between 30 min and 1 hr and 15 min. Dow thanked interviewees for their participation and assured them that their

stories were important. Throughout interviews, Dow used active listening skills, allowing individuals to talk for lengthy periods of time. Verbal and nonverbal cues encouraged interviewees to continue speaking and signaled the value of their testimonies. Dow did not take notes during interviews, which helped to foster a fluid and conversational atmosphere, and used eye contact to put interviewees at ease. She documented her impressions after each interview.

Interviewees shared their life stories and discussed how they felt FASD affected their lives. One interviewee did not seem to understand the terms FASD and FAS, and so he discussed his life in general and the struggles he had while in school and at work. Interviewees appeared to be pleased to share their stories, although half struggled with what to say at various points in their interviews. At times, some individuals were hesitant to answer questions. Dow asked if they would like to skip difficult questions, and several chose to do so. In one case, an individual chose not to discuss legal charges he had incurred when younger, and, in another case, an individual chose not to discuss her previous marriage involving domestic violence. Some respondents struggled to respond to open-ended questions, leading Dow to ask more specific questions. Booth and Booth (1996) find that individuals with learning difficulties often experience difficulty with answering open-ended questions and generalizing from their own personal experiences. When this problem arose, simplifying questions or stating them in a different way helped. Dow used closed-ended questions on high school graduation, independent living skills, and employment towards the end of interviews if interviewees had not previously discussed these QOL indicators.

Dow gave interviewees either a US\$15.00 iTunes or Starbucks gift card at the conclusion of interviews and offered them the opportunity to read, add to, or edit their interviews once transcribed, in an effort to “member check.”¹⁰ One interviewee asked for the transcription; she read the transcript but did not make any changes, saying it was accurate. Dow also asked interviewees if she could contact them with follow-up questions. After analyzing the data and discovering the need for additional information or clarification on some topics, she emailed several interviewees and added their replies to the data. To ensure confidentiality of data, Dow assigned interviewees codes before transcribing their recordings. After transcription, she deleted the recordings. Dow stored consent forms, research-related records, and data in a locked cabinet to ensure security and confidentiality.

Findings and Guidance

Based on Dow’s experience with sampling and interviewing individuals with FASD, we offer the following findings and guidance for other researchers.

Without community agency and gatekeeper support, gaining access to individuals with FASD for interview purposes is difficult. Researchers should approach appropriate community agencies to explore the possibility that they will vouch for the research

agenda, verify the researcher’s expertise and trustworthiness, and facilitate access to individuals who meet the research criteria. Dow connected with an organization that provides diagnostic screening and assistance to individuals with FASD and a residential treatment provider that aids clients who meet the diagnostic criteria. These agencies vouched for her research and agreed to share it with their clients who then could self-identify for participation. Dow gave agency personnel the opportunity to read the research results so they could better understand how their clients viewed FASD, what services they found effective, and where they felt they needed additional assistance. Without the aid of these agencies, Dow could not have located her desired population and established rapport with her interviewees prior to the interviews. Even with assistance from these agencies, Dow still struggled to find adult individuals with FASD to commit to interviewing.

As research has shown, obtaining gatekeeper support is also critical (Kawulich, 2011). Caregivers of vulnerable individuals sometimes erect barriers to research in an effort to shield them from potential harm. Dow found that interviewing parent gatekeepers not only provided rich information on how their children’s cognitive disabilities impacted them but also opened access to those in their care for interviewing. Once parents became comfortable with Dow’s approach, they became more willing to allow her to interview their adult children. Without gatekeeper approval, accessing and interviewing individuals with FASD would have been more difficult. Although they are adults and have the right to make their own decisions, they have limited communication and organizational abilities and rely on their caregivers. They likely would not have agreed to interviews without their parents’ encouragement or permission.

Without relationship building prior to interviews, rapport and trust is hard to establish. Although researchers cannot always establish relationships with vulnerable individuals prior to interviews, doing so can help to establish rapport and trust and create an environment in which interviewees feel comfortable with sharing their life narratives. Of the eight interviewees, Dow knew four from previous work at the agencies she had contacted for her research; she did not know the other four prior to the interviews. Dow found that the individuals she knew prior to interviews were more comfortable arranging interviews, more at ease during the interviews themselves, and more willing to discuss difficult and emotionally charged aspects of their lives than the individuals she did not know prior to interviews. Based on the preinterview relationships, Dow could also ask questions specific to the individuals and gently probe into life events with which she was familiar.

As one example, Dow said in an interview,

Well, I forgot to ask you about your dog. And we should actually talk about that just for a minute. So you had come into the office and asked me to write something up for you to get a service dog? Can you just briefly tell me about that?

Recalling that the interviewee had sought a service dog, Dow knew of a resource the interviewee had used but omitted during the interview. As another example, one interviewee, who was unknown to Dow prior to her appointment, arrived an hour early at the PHH office but left before the interview due to her anxiety. She also missed the second interview but then arrived at the third appointment after discussing her unease with her previous foster parent. Meeting prior to the interview would have likely helped with rapport and minimized her concerns. Although researchers may not always have such opportunities, they should try to find ways to volunteer or spend time in an agency with potential interviewees. While developing rapport with members of the vulnerable population and staff, researchers better understand the lives and challenges of people and ways in which to distribute information about resources.

Individuals with FASD sometimes struggle understanding and feeling comfortable throughout the research process. Researchers must take extra precautions not only to meet ethical standards, ensure transparency, and protect interviewees from discomfort and anxiety but also to create a safe environment for them to tell their stories. Dow reviewed the consent form with her interviewees, explaining the purpose of the research and giving them time to discuss the interview process and ask questions. She reassured respondents that they were participating voluntarily, could skip questions, and could stop at any time. In three cases when Dow was unsure of the individual's cognitive abilities, she requested that the caregiver stay in the room while she explained the informed consent and purpose of the research so they could provide assistance if needed. In one case, the parent stayed throughout the complete interview after it became clear that the interviewee preferred it. In all interviews, when interviewees hesitated, Dow reminded them that they could choose not to answer a question.

To create an environment that is comfortable for interviewees, researchers should allow them to choose the interview location or identify a location where they believe they will feel at ease. Dow interviewed individuals at their homes; at the PHH office, where they had received services; and, by one interviewee's choice, in Dow's home.

Before starting interviews, researchers should attempt to establish rapport with interviewees. Rapport building can occur through making small talk and using self-disclosure, such as finding a common interest or discussing a place that both the interviewer and interviewee have visited (Dempsey et al., 2016). Since Dow had graduated from a local high school from which some of her interviewees had also graduated, this established common ground. Dow also found that face-to-face interviewing allowed her to maintain eye contact and read and react to body language and other social cues. Dow allowed interviewees to tell their stories at their own pace, waiting to ask potentially difficult questions until interviewees were more comfortable.

Dow used encouraging and reassuring phrases to affirm interviewees. For example, in one interview, she said, "Well, sounds like you have a good plan for the future." In another, she

said, "Well, you're good at this interview." She listened actively, responding to interviewee comments with affirmative words like "good" and "okay." Dow minimized the prospect of interviewees feeling frustrated or uncomfortable by allowing them to skip questions. For example, in one interview, she said, "That's one of those times when you can say, 'I don't want to talk about that.'" At the beginning and end of interviews, Dow expressed appreciation for interviewees' time and effort and gave reassurances to interviewees that they had done well. When one interviewee closed with "I feel I did bad on answering the questions," Dow responded, "No, that's what I was saying earlier. There are no right or wrong answers. It's your story. So you did great! Thank you!" Most interviewees expressed positive comments at the close of interviews.

The priority should be protecting interviewees. This includes not only guaranteeing confidentiality, ensuring ongoing consent, and providing a comfortable interview environment but also giving them the opportunity to decline discussing sensitive topics such as past sexual history or inappropriate or criminal behavior (if applicable). Although understanding more about all aspects of the lives of individuals with FASD would be beneficial, this should not come at the risk of inflicting pain or inducing trauma.

Individuals with FASD demonstrate varying communication styles and abilities during the interview process. Because individuals with FASD or other cognitive disabilities often have impaired mental processing speeds, researchers should allow adequate time for interviewees to understand questions and express their thoughts. Interviewees need time to tell their stories. Researchers need to look for signs that interviewees are uncomfortable with questions and remind them that they can skip these questions, are struggling to understand questions and repeat them in different ways, and are having difficulty in expressing their ideas and probe delicately for more information. Dow observed that individuals with more cognitive challenges gave much shorter answers, while still providing valuable insights into their lives. In these interviews, Dow provided more input, gently asking for clarification and rephrasing questions, while avoiding asking leading questions, injecting personal bias, and pressuring respondents.

Dow asked short, simple, and straightforward questions, increasing the prospect that interviewees would answer them. These questions were especially fitting for interviewees who were not confident speakers. When interviewees veered off topic or made confusing statements, Dow used active listening tactics and asked short, follow-up questions. For example, in one interview, when a respondent discussed her difficulty with learning at school, particularly reading, Dow said, "OK, so the comprehension was difficult for you?" Dow also restated responses in simple and direct ways for agreement. Dow found that vague, open-ended questions consistently yielded little information, in line with other research (Beail & Williams, 2014). At the end of each interview, Dow asked, "Do you have anything else that you want to share?" Respondents almost always answered "no." Vulnerable populations, especially

those with mental impairments, respond better to focused and direct questions. When researchers have little or no experience working with people with cognitive disabilities, we recommend that they receive special interview training.

Individuals with intellectual disabilities have a tendency to provide socially acceptable responses—that is, answers that they believe are correct, appropriate, or exemplary. Caregivers often report that individuals with cognitive disabilities are too easily led, try hard, and want to please others (Streissguth et al., 1998, p. 44). Dow's research revealed that interviewees were often bullied or ostracized and their words and demeanor showed a need for assurance and acceptance. As such, researchers should avoid leading questions and give interviewees adequate time to express their own thoughts. If researchers find it necessary to simplify questions, they must be careful to avoid injecting bias into the revised questions. Dow observed that her interviewees tried to provide "right" or positive answers. Thus, she asked questions in a direct and objective way and delicately probed about issues with which she was familiar, while also allowing interviewees to move on when they wanted, in accordance with the ongoing consent principle.

Conclusion

In recent decades, research practices have evolved to better incorporate the perspectives of vulnerable populations. This has ensured that individuals have a voice in the development of research about them, increased the validity of research, and fostered partnerships between individuals and resource providers.

Recognizing that wide variation among vulnerable individuals exists, we focus specifically on individuals with FASD. Conducting research in this area has myriad challenges. Individuals' and gatekeepers' desire for privacy is a barrier to identification and access. We advise working with agencies to determine whether they are willing to solicit volunteers for the research. Scholars should clarify the benefits of their research to agencies and individuals and guarantee that neither a willingness nor refusal to participate is associated with disadvantages in accessing services. When possible, researchers should also establish rapport and trust with the prospective interviewees before interviews. Dow used her networks at the FACES Diagnostic Clinic and the PHH, two agencies working with individuals with FASD, and at UAF, to build her sample. Families and individuals self-selected to participate, and then Dow and interviewees arranged the interviews.

Individuals with FASD often suffer from cognitive disabilities. As such, taking extra care to ensure that they participate with voluntary and informed consent is essential. Rather than only providing the protections to interviewees at the start of interviews, we advise reminding them about voluntary and informed consent throughout the entire interview process. For example, if respondents struggle to respond to sensitive questions or act uncomfortable, interviewers should offer reminders that they can skip questions. Dow used this technique in her interviews with success. Given the variation in

communication styles among individuals with FASD, it is incumbent upon researchers to continually assess interviewees' comfort levels and respond appropriately to any indications of unease, desire to move to the next question, or eagerness to end the interview.

Many vulnerable populations, especially those with impaired mental capacity, remain largely invisible to mainstream society, and their needs oftentimes go unmet. We argue that rather than avoiding research with vulnerable populations, in this case, individuals with FASD, researchers should take steps to overcome barriers to access these individuals and proceed cautiously to protect their rights and ensure their comfort during the research process. A better understanding of their lives, viewpoints, and struggles through such research can lead to the provision of resources that could enhance their quality of life. *Their* perspectives must inform policy aimed at addressing *their* needs.

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Notes

1. The University of Alaska Fairbanks institutional review board approved coauthor Brenda Dow's research (IRB 829897-1) on April 6, 2017.
2. Collateral information might include general information on the population under study or confirmation of diagnosis meeting research criteria.
3. We differentiate between cases and interviews. The study included 18 cases of individuals with fetal alcohol spectrum disorder (FASD): 14 cases had only one interview (either an individual with FASD or a parent), while 4 cases had two interviews (three with one parent and one individual, and one with two parents), for a total of 22 interviews.
4. We use the term "parent" to refer to an adoptive parent or former or current long-term foster parent. No biological parents volunteered to be interviewed. All long-term foster parents had lived with the individual with fetal alcohol spectrum disorder for at least 4 years. All participants lived in interior Alaska except one family (who lived in a small town near Anchorage).
5. Unfortunately, the snowball sampling method did not lead to any further interviews.
6. Although some cases in Dow's dissertation research include legal minors, only the parents were interviewed.
7. Dow had worked at Presbyterian Hospitality House for over 8 years.
8. Dow had previously worked with the Diagnostic Clinic's Coordinator through a position at Presbyterian Hospitality House, and

thus the coordinator agreed to assist with the research. The director of this agency was notified of the ongoing research, but since no research was conducted within the agency, and the diagnostic coordinator only sent out an email with Dow's contact information so that individuals and their families could self-select into the research if they so desired, Board of Director's approval was not necessary.

9. Parents, only, provided interviews for the other 10 cases.
10. Dow stated that interviewees would receive the gift card of their choice in the informed consent form. However, she did not use the gift card as an incentive for interviews ahead of time.

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