

Qualitative Interviewing for Special Populations:
Young Adults with Intellectual and Developmental Disabilities

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Abstract

Postsecondary education for individuals with intellectual and developmental disabilities (IDD) is an emerging area of research. Although there has been increasing interest and program development in this area, there is limited research that explores interviewing as an aspect of qualitative study in such specialized postsecondary programming. This paper seeks to identify various forms and components of the interview process including an historical and developmental perspective, and interviewing in special education concerning researcher identity, interview skills, as well as finding voice and power. A reflection and critique' is also provided.

Keywords: Special populations, individuals with IDD, history, development, interview, researcher identity, interview skills, voice, power

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Historical Significance and Qualitative Inquiry

Over the past several years, there has been a significant increase in the development of postsecondary education programs for young adults with intellectual and developmental disabilities (IDD) (Grigal, Hart & Weir, 2012; Papay & Bambara, 2011; Think College, 2012).

A marked shift in historical and educational philosophy has challenged the traditions and current practices of higher education, particularly regarding equity and benefits for students with disabilities (Hart, Grigal & Weir, 2010; Mclaughlin, 2010). With the passage of the Higher Education Opportunity Act of 2008 (HEOA; P.L. 110-315), legislation set federal guidelines creating a path for students with disabilities to access higher education (Grigal, Hart & Weir, 2013; Madaus, Kowitt, & Lalor, 2012).

Although there has been increasing interest and program development in this area, there is limited research that explores interviewing individuals with IDD as an aspect of qualitative study in specialized postsecondary programming. This paper seeks to identify the various forms and components of the interview process including an historical and developmental perspective, and interviewing in special education with concerns related to researcher identity, interview skills, as well as finding voice and power.

“The qualitative research interview attempts to understand the world for the subject’s point of view, to unfold the meaning of people’s experiences, to uncover their lived world prior to scientific explanations” (Kvale, 2006). This importance lies in “the identity work that emerges in the interview is a product of the questioning as much as it is a product of the answering” (Kvale, 2006). The following represents qualitative inquiry regarding this area.

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A Developmental Perspective

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It is important for the researcher conducting a study within the context of a postsecondary education program for young adults with IDD to consider the developmental differences of the consenting participants and how these differences may affect data collection through interview. Most postsecondary programs include individuals with diverse intellectual and developmental disabilities (ex. Down Syndrome, Autism, Traumatic Brain Injury, Cognitive Impairment), therefore of whom may express different cognitive ability levels (Hart, Grigal & Weir, 2010; Papay & Bambara, 2012; Think College, 2012). These differences may impact an individual's ability to comprehend questions posed in an interview, and as such, can present certain complexities for the researcher when interviewing this unique population of young adults (Holstein & Gubrium, 2003; Saldaña, 2016). *are ctes specific to?*

In these sensitive cases, an approach to interviewing is dependent upon an understanding of human development through intensive review of the relevant literature as to inform the researcher about differing disabilities in young adulthood in order to provide insight and corroboration for subsequent findings (Saldaña, 2016). In addition to acquiring this information, the researcher might view more recent understandings of human development that include "acknowledging the unique character, unpredictable and diverse trajectories, and complex interrelationships of gendered individuals exercising agency within varying social contexts through particular periods of time" (Saldaña, 2016, p. 106). In this sense, information gleaned from individuals with IDD enrolled in postsecondary programs in inclusive higher education could be regarded as context-bound, or local, and interviews conducted within this setting may reveal a range of experiences and observation derived from the construction of knowledge within this setting (Lincoln & Guba, 2013) as well as over an individuals' academic journey.

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Interviewing in Special Education

What makes us uniquely different as humans than other animals is our ability to assign meaning to things (Patton, 2015). Qualitative research delves into, documents, and interprets the process of meaning-making. Because this process often grants insight into meanings not previously understood, the researcher can be recognized as the instrument and holds a vital role in providing a way for these meanings to emerge (Lincoln & Guba, 2013; Patton, 2015).

Researcher Identity in Special Education. Qualitative research is personal and involves researcher “background, experience, training, skills, interpersonal competence, capacity for empathy, and cross-cultural sensitivity” in influencing engagement in fieldwork (Patton, 2015, p. 3). For the researcher in the field of special education, notably if the role is that of an insider, recognizing one’s affect on data collection and subsequent related interpretations is essential for maintaining an obligation and commitment to qualitative inquiry (Leigh, 2013; Patton, 2015). This reflexivity is uniquely valuable regarding the function of special education researchers in the process of interviewing young adults with IDD enrolled in postsecondary programs situated within the higher education setting, as well as for the perspectives that are produced from being associated with it (Leigh, 2013).

Moreover, because of these interrelated positions, issues tend to surround the legitimization of the statements researchers make in findings about the experiences of others (Lincoln, & Guba, 2013). Therefore, appreciating the value of this role is vital when revealing new understandings through the first occurrence of a “realization” of original experience made known by the individuals with disabilities and for the process of meaning-making (Lincoln & Guba, 2013, p. 55), particularly as these experiences are quite frequently novel in the field of special education and add to the limited body of knowledge that currently exists in literature.

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Interview Skills in Special Education. Interviewing is a skill that, although practiced in some disciplines such as social work, counseling, and nursing, most often develops with experience (Corbin & Morse, 2003). Interviews can be seen as both sensitive and powerful (Kvale, 2006). For example, this combined approach was used in a qualitative study to comprehend the experiences of postsecondary students with diverse disabilities aimed at uncovering the processes of meaning-making as students constructed their own realities “within an environment supportive of realization and change,” therefore elucidating vast chasms still remaining in literature, policy, and the presence of ability-diverse populations in postsecondary education (Hutcheon and Wolbring, 2012, p. 40).

The notion of sensitivity may be understood as more of a personality trait than a developed skill, although ^{it's} recognized in qualitative research as a necessary attribute for minimizing the distress some participants may encounter (Corbin & Morse, 2003). Sensitivity can be fostered and developed through interactions with others (Holstein & Gubrium, 2003, Kvale, 2006). Perhaps the most relevant feature of interviewing with sensitivity as related to individuals with disabilities is the ability to adapt to the needs of the respondents, including the need for pacing, taking breaks, eliminating painful discussions, and altogether ending the interview if necessary (Corbin & Morse, 2003). Some of these features are in direct alignment with the supports commonly afforded individuals with IDD within specialized programs in the postsecondary education context (Hart, Grigal & Weir, 2010; Papay & Bambara, 2012). In these settings, interviews with individuals with disabilities may also necessitate simplified language, questions repeated and/or prompted, interviews kept to a shortened length and/or repeated (in order to gain rich data with depth of information), within a calm, comfortable environment with minimal distractions and close proximity to the interviewer (Ingram & Graff, 2016).

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Not all individuals with intellectual and developmental disabilities present as expressing difficulties that require sensitivity and support, in fact, interviewers not familiar with working with this population may not recognize that their interviewees *have* cognitive impairment. Some individuals may present well, demonstrate good social and communication skills, and respond to most questions asked (Holstein & Gubrium, 2003). In this case, it is entirely possible for the novice researcher to conduct a full interview and not be aware of that the information conveyed, while complete in scope, may indeed not be accurate (Holstein and Gubrium, 2003).

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Conducting a pre-interview phase may assist the researcher in circumventing issues related to cognition and managing an individual's participation in the interview. The first steps may involve explaining the purpose of the interview, repeating the material as necessary, and going over the consent form if needed in order to determine if the participant fully understands the document (Corbin & Morse, 2003). The next step may include explaining the *process* in simple language, assisting individuals in understanding what to expect in the interview and how to answer questions, including providing an example through mock scenario (Ingram & Graff, 2016). In addition, an example may be provided that offers what to do when a participant *does not know an answer* as to prevent an inaccurate response in the expectation of faithfully answering an interviewer's question (Ingram & Graff, 2106). A last step includes establishing rapport, often with small talk, in an attempt to create a level of comfort and garner a degree of trust (Corbin & Morse, 2003; Holstein & Gubrium, 2003). This human connection sets the tone for the ensuing interview and the foundation for reciprocity, or the exchange of information (Corbin & Morse, 2003). In this capacity, intimate details are shared in a back and forth manner, with the researcher giving of themselves in the act of being present and honoring the stories delivered by the participant by an active engagement in the process (Corbin & Morse, 2003).

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Finding Voice and Power in Special Education. The goal of developing specialized postsecondary programs for student with disabilities has not been to parallel K-12 special education services at the college level, but to reflect authentic, inclusive education pedagogy and culture (Think College, 2011). For students with IDD, being a member of a college campus, participating in classes with students without disabilities, and learning to navigate an environment with a higher set of expectations presents opportunities for the development of skills needed for success in adult life (Hart et al., 2010). In order to gain from this experience, students with disabilities need to be actively engaged in the transition to postsecondary education and demonstrate self-determination by expressing skills in autonomy, self-regulation, psychological strength and self-realization (Wehmeyer, Argan, & Hughes, 2000; Palmer et al., 2012). In this way, students with disabilities will be prepared to be active, equal partners in their own educational journey (Wehmeyer et al., 2000).

Qualitative researchers can find a role in assisting to give voice to individuals with IDD as they embark upon this unique process of *transition* and *transformation* to elicit their “worldview, life satisfaction, and personal values” associated with this unique experience (Saldaña, 2016, p. 106). One crucial reason for interviewing young adults with enrolled in specialized postsecondary programs is to allow them to speak to “their own interpretations and thoughts” (Holstein & Gubrium, 2003) rather than concede the many stakeholders who have spoken for them over their K-12 academic tenure. NICE

Power dynamics can be understood to occur in all studies involving interview, as the researcher has control over the process by simply holding the position of the one asking the questions (Holstein & Gubrium, 2003, Kyale, 2006, Lincoln & Guba, 2013). This is particularly important when examining vulnerable populations because their seeming disadvantage maintains

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their position in society as always those of the “researched” and never the “researchers” (Holstein & Gubrium, 2003). In this regard, the voice that is “heard” is commonly determined by the individual who constructs the new knowledge, and often this individual represents a “privileged” class or group that consists of a consensual voice of those members of this group (Lincoln & Guba, 2013, p. 57).

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Interviewers can be sensitive to this power imbalance and give opportunity to participants as their voices are often marginalized in adult culture (Holstein & Gubrium, 2003). Vulnerable populations, in particular, are often seen as not having any control over the production or distribution of the research, however there are ways to empower participants by involving them in the research process (Holstein & Gubrium, 2003).

One way to resolve this situation is to include participants as collaborators in the research study, training them to gather data and act as full contributors in forming the representations that are constructed (Lincoln & Guba, 2013). In some instances, sites will not allow the researcher to conduct research unless a co-researcher is assigned who is “native” to the site (Lincoln & Guba, 2013, p. 58). In this sense, those who are being studied are afforded a certain level of protection by having a measure of control over the representations that are made of them, as well as have power over certain issues, claims, and various concerns that arise from the local setting (Lincoln & Guba, 2013). Some sites also require that a portion of the researcher’s time be spent supporting the issues that are of local interest, although these types of situations can often be met with negotiations that serve to honor all parties involved and attend to hearing the voices studied (Lincoln & Guba, 2013). As interviewers, the researcher’s goal is to acquire knowledge about the world of our participants “in their own terms” adding new perspectives and greater depth to collected data and analyses (Holstein & Gubrium, 2003).

this is for a critique

For every construction of new knowledge, the foundation is based in the “values projected by the voice that shaped it,” and every construction is created in the framework determined by “social, cultural, historical, political, economic, ethnic, and gender positions” held by the constructor (Lincoln & Guba, 2013, p. 58). Because of this accepted understanding, research concerns have arisen challenging the authority of social scientists and the representations of those who speak for “the Other” (Lincoln & Guba, 2013, p. 58). By representing research participants by their own descriptions, as exemplified in the case of individuals with IDD enrolled in postsecondary programs, we avoid holding them apart as “Other” (Fine, 1994). Again, the solution offered is to include the Other in the processes of research and the presentations of this research (Lincoln & Guba, 2013, p. 58).

p# Researcher Michele ~~Fine~~ (1994) suggested that in order to resist Othering, researchers needed to “work the hyphen” -or actively pursue the relationships researchers have with their participants in order to better understand them. She proffered that the researcher should be brought into the descriptions provided by the participant and interpret the negotiated relations between the researcher and the researched to prevent viewing the participant as Other. This approach added another level of depth in understanding adding to *how* research might be valued and conducted. Fine acknowledges the researcher’s context and proposes that race, class, gender, and voice be a part of the research and that the outcome will be better data and will assist in drawing a more accurate picture of the data as well as the participants, and will move researchers to be more honest in revealing analyses, interpretations, and presentation of the data.

This issue addresses the legitimization of qualitative research and the questions surrounding the rights of the researcher to represent others, especially those who, like individuals with IDD enrolled in postsecondary programs, may not have access to power through voice.

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Reflection and Critique

With regard to interviewing individuals with IDD who are enrolled in specialized postsecondary programs seated within the context of inclusive higher education, the presence of cognitive impairment does not negate the ability of the researcher to conduct in-depth interview activities, nor does it preclude engaging in an interactive relationship that can afford useful data through a collaborated and negotiated interpretation. Although recognized as a potential challenge, following recommended steps that treat individuals with IDD with certain sensitivity will allow for the completion of successful interviews and the gathering of rich descriptions in data collection. Researchers can further support their own understandings by learning about human development and examining the relevant literature and related references specific to the developmental domain in order to ready themselves for approaching special populations in study.

Consideration was also given to researcher skills in interviewing techniques and whether these reflected an ability to meet the needs of special populations, including individuals with IDD, with such sensitivity. It may be important here to examine if the novice researcher has undergone any form training or taken any courses that provides them with the skills they need to conduct an interview and to not cause distress, and also to know the methods of recognizing and diffusing such instances. This appears to be a much-needed area in training qualitative researchers with both the appropriate methods and feedback for conducting future studies.

Researcher Michelle Fine (1994) found in her research that it was important to consider whether participants might resent the researcher speaking on their behalf as an Other, that self-examination may prove collusion with existing structures of domination, and to give more authority, or voice, to participants' own words, rather than through the worldview that shaped the researcher's lens in study. She suggests the creation of friendly communities that will help

support the researcher in attaining a more true understanding of the founded voices and interpretations of analyses. This may be especially important to heed with respect to special populations and how researchers might consider the ways they can benefit a community at the outset in which their tentative research will be conducted, and therefore be able to create opportunities for reciprocity in giving back in that context, as well as for the very real applications their research may deliver.

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Fine's shared experiences elucidate the difficulties researchers discover related to power and how these challenges affect the ability to create acts of reciprocity, as these may shift from one environment to another, therefore it is imperative that researchers consult with those in the field regarding the established norms of the group in context, the rules governing reciprocity, and exhibit a willingness to work collaboratively and negotiate involvement in interpretations, as opposed to acting as an independent agent for change.

In sum, as the researcher seeks to understand individuals with IDD who are enrolled in specialized postsecondary programs situated within the context of inclusive higher education through qualitative study with interview, examining the processes of transitions for which they move in life's phases, it is incumbent upon the researcher to consider the cumulative experiences that might influence and affect how and what can be presented during these interviews. In this way, qualitative methodology becomes an asset for discovering new knowledge and solving problems of humanity.

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