Article

Narrating Developmental Disability: Researchers, Advocates, and the Creation of an Interview Space in the Context of University-Community Partnerships

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Abstract

This paper examines the narration of developmental disability through interviews between participants, researchers, and members of community organizations serving the disabled population, in the context of university-community collaborations. These kinds of collaborations are extremely important for researching vulnerable or hard-to-reach populations, which often face lower levels of physical, mental, and social well-being as a consequence of shame, stigma, or discrimination. Community collaboration can thus be invaluable for reaching members of marginalized populations, who may be difficult to locate or otherwise avoid contact with outsiders, because it provides members of a research team with local knowledge of a population, a means of accessing possible participants, and legitimation for the project. I suggest, however, that although the researcher's externality may initially invite skepticism toward the investigation from participants, it can also benefit them by providing a forum for catharsis. Based on a pilot study I conducted with a community advocacy organization for the disabled, I note that some participants expressed an appreciation for being able to discuss certain emotions and experiences during interviews with an outsider who was not involved as a caseworker. I conclude that the presence of a trusted community advocate and a researcher at an interview affects a participant's narrative by providing a safe space for participants to voice their stories to outsiders.

Introduction

Academic partnerships with community organizations are being used increasingly to address health issues related to vulnerable, hard-to-reach and "hidden" populations, given that "local knowledge of and access to members" (Benoit, Jansson, Millar, & Phillips, 2005, p. 265) of a population are often necessary to conduct sustained and reliable research. Collaboration, though potentially protracted and complicated, has reported advantages for researchers as well as members of the organization and the population itself: Research projects are commonly legitimated as relevant to, and connected with broader public issues, while possibly short-staffed organizations with high demands and limited resources may benefit from researchers' time and expertise in education, training, policy analysis, or advocacy (Ebata, 1996). Successful collaborations therefore have the potential to increase the well-being of hard-to-reach populations by generating a body of research on otherwise underreported conditions, needs, and afflictions they face.

The type of research project to be undertaken and the members involved inevitably affects the way in which collaboration will occur. Although researchers generally partner with organizations or groups which can act as gatekeepers to populations that are otherwise isolated (Benoit et al., 2005; Caine, Davidson, & Stewart, 2009; Kingsley, Phillips, Townsend, & Henderson-Wilson, 2010), interaction between researchers and participants is by no means strictly defined on the basis of tensions or misunderstandings between in-group and out-group members. This paper examines researcher collaboration in a pilot project with a community advocacy organization that works on behalf of parents with developmental disabilities. Many developmentally disabled parents face challenges in attempting to raise children as a consequence of stigmatization, socio-economic disparity, and unacknowledged medical issues, and as is often the case, loss of custody. High poverty rates and a potential sense of shame about their disability—what Donna Reeve (2002) calls "internalized oppression," (p. 495) in which individuals of a marginalized group incorporate and accept "prejudices against them within a dominant society" (p. 495)—often mean that parents with developmental disabilities constitute a hard-to-reach, vulnerable population. The parents who participated in the project were all clients of the organization as a result of having one or more children removed from their care. They were receiving social support, instruction, and subsidies in order to foster stability and proper parenting skills. The parents each requested that an advocate with the organization be present at their interviews, and many were initially reticent. Yet, throughout the process, the parents became more open about their experiences and even reported, as the advocate noted after the interviews had been conducted, cathartic benefits of sharing their stories with someone who was not affiliated with the government or legal organizations they were so often involved in.

While the importance of the interview setting has been well-documented in terms of the success of the interview (Gibson & Brown, 2009; Roulston, deMarrais, & Lewis, 2003), I suggest that the people present in an interview setting matter with respect to the kinds of stories that can be told. It is understood that the presence of an advocate, gatekeeper, or someone with whom the participants are familiar or trustful of can lead to participants telling more detailed or personal stories than they may have otherwise divulged to a researcher alone. As a complement to the model of collaboration in which researchers and community organizations work together to generate research about participants from a population, however, I note a dynamic in which I as an outside researcher influence the participants' narratives in a way that indicates a perspective different from the one generated by interaction solely with advocates or caseworkers and other members of "the system". While the externality of the researcher can sometimes lead to

skepticism or distrust of the project on the part of participants, it can also, alternatively, provide a forum for participants to express problems on an emotional level that they may have assumed to be unimportant to caseworkers. I will examine the creation of these relations as they are delineated by the context of the interview.

Literature Review

Stigmatization and discrimination of those with mental health conditions is a pervasive issue with wide-ranging implications for mental and social well-being (Gormley & Quinn, 2009; Pescosolido, Martin, Lang, & Olafsdottir, 2008). Stuber, Meyer, and Link (2008) argue that the experience of stigma engenders "exposure to negative attitudes, structural and interpersonal experiences of discrimination or unfair treatment, and violence perpetrated against persons who belong to disadvantaged social groups" (p. 351). The successful integration of the mentally disabled into the community is thus partially dependent on public attitudes toward mental illness and retardation, given that such attitudes can affect, according to Schwartz and Armony-Sivan (2001), where the disabled can live and the kinds of jobs they can hold, as well as "the quality and availability" (p. 403) of services and treatment they are offered. Consequently, some members of the disabled community regard health care workers in medical professions as ineffectual or paternalistic, and therefore contributing, in some instances, to social oppression (Crisp, 2000).

The developmentally disabled may be, as a result, difficult to access for outsiders. Although they do not constitute a "hidden" population as Heckathorn (1997) defines them, which typically have unknown population sizes or boundaries and often refuse to participate in research owing to the "stigmatized or illegal behavior" (p. 174) of the members, people with developmental disabilities may refuse to cooperate with outsiders who appear potentially discriminatory, or deny having a disability entirely. Higher rates of unemployment and socio-economic instability can also make members of the population hard to reach.

The difficulty in reaching certain populations is one of the main reasons Benoit et al. (2005) suggest that academic researchers are increasingly collaborating with community organizations. Members of these organizations, generally separate from research institutions, may be drawn from "government, agencies, institutions, and organizations" (Ebata, 1996, p. 72), or they may be "the citizenry of a particular locale" (p. 72). Community organizations are thus likely to be in direct contact with the populations they serve, exemplified by the organization I worked with, to which clients were generally referred for support services after they were deemed in need by Child Welfare Services. Working with community organizations can, then, shed light on potential participants and where to find them, and, as a consequence of the researcher's affiliation with the group, lend legitimacy to research projects in the eyes of possibly skeptical population members. Gaining a local knowledge of the population is also necessary. As Kingsley et al. (2010) point out; there exists an obligation to root research on marginalized or disadvantaged populations in the communities they live in, to avoid exploitation or hazard that could result from misunderstandings of an external researcher (p. 4).

Though successful collaborations between researchers and organization workers are not always feasible (LeGris et al., 2000), many researchers stress the importance of community collaboration as a means of generating pertinent findings for public policy by joining with front-line workers with first-hand experience (Jansson, Benoit, Casey, Phillips, & Burns, 2010); validating the image of public research universities as connected to the community (Eccles, 1996); increasing the life chances of community members with failing socio-economic infrastructures (Tourse et al., 2008); being able to provide evidence- and patient-based care (Jarvis-Selinger et al., 2008); and

the need to negotiate different backgrounds and disciplines to achieve relevant research to implement in practice (Hinshaw, Chance, & Atwood, 1981). As Power, Cumbie, and Weinert (2006) note, this "growing awareness of the need to understand the impact of community dynamics and sociocultural factors on health" (p. 2) means that there has been an increase in "orientations to inquiry that stress community partnership, action for social change, and reductions in health inequities as integral parts of the research enterprise" (p. 2).

The ways in which hard-to-reach or disadvantaged population members interact with, and benefit from, the work of researchers in their communities, however, varies. Researcher association with a community organization can, as I mentioned previously, increase the legitimacy of the project for the participants. Yet, it is not always enough to suggest that the combination of researchers working with groups in the community invariably leads to the generation of fruitful data that neither one nor the other was able to develop working on their own. Though researcher expertise is said to be one of the crucial components that members of the academy can bring to university-community collaboration, researchers are themselves typically outsiders: Ross Crisp (2000) notes, following a tradition of social constructionism, that his research on the disabled "focused upon the insider's perspective in which persons with disabilities were regarded as expert contributors in the research process, and in which the researcher as outsider/learner incorporated the views and values of insiders into the research program" (p. 356). While researchers may be experts in designing a research program, they are not authorities on the participants' lives *per se*, meaning that partnership between academy members and community members is not strictly the synthesis of theoretical knowledge and first-hand experience.

What, then, is the character of the relationship between researchers and participants in the process of university-community collaborations? How does someone external to a marginalized population affect the research generated about a population? My own research was ethnographic in nature, involving conversations with workers at a community organization and interviews with participants. It is therefore the relationship developed in the course of interviewing that I will examine in particular, given the attention paid to the ability of participants to find a voice or reconcile personal dilemmas through narratives and storytelling. Indeed, therapeutic benefits of narrating crisis, trauma, and suffering have been noted as ways in which qualitative researchers can assist the communities they are investigating (Atkinson, 2002; Priya, 2010; Rosenthal, 2003).

The nature of researching vulnerable, disadvantaged, marginalized, or hard-to-reach populations, however, demands a consideration of both benefits and harms of relating useful and interesting, albeit potentially painful or traumatic, narratives to researchers (De Haene, Grietens, & Verschueren, 2010; Hewitt, 2007). Aside from contending with ethical questions on the protection of participants from any harm associated with research (Clark & Sharf, 2007; Halse & Honey, 2007; Mertens & Ginsberg, 2007), researchers must also take into account the structure and context of the interview itself, given the distribution of power between researcher and researched. Though many qualitative researchers attempt to avoid the dichotomous power relations of "researcher" and "respondent" found in traditional models of interviewing (Mayan, 2009, p. 70; Roulston, Baker, & Liljestrom, 2001), the possibility of rearranging conceptual roles in a democratization of the interview process raises some ethical dilemmas and methodological problems in itself (Karnieli-Miller, Strier, & Pessach, 2009). I suggest, however, that the nature of the research relationship between participants and researchers acquires another dimension in the context of a university-community partnership, if the researcher represents an outsider who is willing to empathize with members of a vulnerable population. Although power in these circumstances is not necessarily redistributed on an even basis, the researcher's externality to the system in which participants are so often involved presents the notion that someone who is not

directly fulfilling a task related to the participant's disability or custody case is interested in his or her story.

Research Design and Methods

The methodological considerations discussed in this paper stem from an exploratory pilot study done in cooperation with a regional community advocacy group in the province of Alberta, as part of a graduate-level course in qualitative methods. The study itself was therefore conducted over a period of only four months and involved a small group of participants. Consequently, the findings presented in the paper are a first-person commentary on the process of engagement with participants, aimed at understanding both interaction with participants and researchers as participants. The community organization, which was also part of a larger project concerning the history of eugenics in Alberta and the sterilization of the disabled, was largely interested in the continued stigmatization of parents with developmental disabilities as incapable, in spite of the repeal of the Sterilization Acts in 1975. Though I developed a project outline with the organization's CEO, he was often very busy and limited in the amount of time that he could devote to the project itself. Thus an advocate helped coordinate most of the project's technical aspects. The study consisted of document analyses of provincial child protection legislation (which implicitly defined what an incapable or unfit parent looks like), and interviews with parents who had experienced custody battles after being deemed unfit (which provided some insight into how the parents experienced the effects of the legislation).

I interviewed four parents in total, during three interviews which took place over the course of a month. Each interview was based on a semi-structured format with open-ended questions, and they ranged from 50 minutes, to an hour, to an hour and a half. Although I developed and posed the questions in the interview guide, I was accompanied by the advocate who was known to the participants and helped develop rapport by bridging the gap between in-group and out-group members, as well as providing prompts for the parents. The first interview was recorded, at the request of the participants, in writing only, while the other two were audio recorded. The first interview was, therefore reconstructed as closely as possible in my notes, while the second and third were transcribed immediately following the interviews. These interviews were used to generate data on the participants' experiences with Child Welfare Services, state subsidies, and community support networks during the course of custody battles, and their opinions of the process. They were then coded, alongside legislation documents, for themes.

Because the parents belonged to a population which is not always immediately accessible to researchers, all participants were recruited by the organization, which believes that sharing and recording the stories of the developmentally disabled is crucial to rectifying social injustices. The parents were each receiving support from the organization, which advocates on behalf of the disabled in order to help integrate them into the community and live as independently as possible. Both the organization and the researcher attempted to minimize risk for the participants as much as possible at the level of recruitment and in the interview process. The participants were selected by the advocate, who accompanied me to the interviews, on the basis of availability, the level of support they had received (i.e., although the parents were still grieving their custody losses, they were enrolled in parenting classes, involved with support groups, and receiving subsidies such that they were no longer in an immediate stage of personal crisis), and their willingness to be interviewed. The participants were made aware of the subject matter of the interviews by the advocate prior to meeting with me as a researcher, so that they were able to agree or disagree to be interviewed with an understanding of the sensitivity of the topics. Those who agreed to be interviewed were also permitted to stop the interview at any time after they began their participation, or to request that some information disclosed not be recorded. Finally, owing to the

role of the advocate in the interviews, to be discussed below, the participants disclosed nothing to me about their children, families, or cases that the advocate was not already aware of. Thus while they may have expressed their concerns from a different perspective or with more feeling with me during the interview, someone the participants trusted was always available to ensure that sensitive topics were dealt with appropriately, and to assist the participants during and after the interviews with questions or concerns.

All names of the participants and their children have been anonymized (though, it is worth noting, some began to share their stories publicly at conferences around the time of, or after the interviews). In keeping with the philosophy of the organization, which holds that social constraints on the disabled can be as much of a problem as a disability, the interviews were designed to avoid pressing the issue of disability unless the participants discussed it. This was especially important given that some of the organization's clients would not have classified themselves as disabled. Instead, questions dealt with participants' experiences as parents, the kinds of jobs and volunteer work they did, whether they owned their home or not, among other social factors.

The participants included Sandra and Doug, a couple whose only son, 19-month-old Matthew, had been removed from their custody immediately after he was born. Sandra and Doug were both physically and developmentally disabled. My second interview was with Stephanie, a single mother with a developmental disability who had several children apprehended and adopted out. Her two youngest children were removed from her home a month before the interview, and she was pregnant with another child at the time. My final participant was Rachel, a developmentally disabled mother who had lost her six-year-old son after reportedly neglecting him. She had made changes in her life, however, which allowed her to keep custody of her nine-month-old daughter.

External to "the System": Creating a Space for the Developmentally Disabled to Narrate Their Experiences

I began this project with an informal meeting with the CEO of the organization in order to outline the basic tenets of the project. We discussed the ways in which parents with developmental disabilities are still assumed to be emotionally and intellectually incapable of being parents. Although legislation promoting the sterilization of disabled women and men—aimed at reducing the transmission of ostensibly undesirable biological traits—no longer exists, the developmentally disabled often still experience investigation into their parenting abilities as a consequence of their conditions. Many of the clients of the organization encountered other socially disadvantageous circumstances as well. Stigmas about developmental disability have, for example, been known to impact an individual's employment status, which, in turn, affect his or her socio-economic status. Other clients had suffered sexual, physical, or emotional abuse at the hands of caregivers or family members. The population from which the participants would be drawn, then, had often suffered on other accounts besides the removal of a child or children from their care, owing to a socially ingrained attitude about disability that extends beyond prejudicial and harmful legislation.

The way in which the interviews were conducted was therefore crucial to the success of the project. There were likely to be complexities in interviewing clients belonging to the organization: Some might be fearful to tell their stories because there had been cases in which a client's revealing parts of his or her life history had resulted in investigations by Child Welfare Services. The organization considered that it was very important, however, to record the stories and experiences of the parents, in keeping with their larger project of "honour[ing] the voices and stories of individuals with developmental disabilities, to ensure their stories are not lost, denied or ignored" (Hughson & Uditsky, 2006, p. viii). Because I was not responsible for recruiting the

participants for the project, my ultimate methodological concerns were related to the interview itself: While developing rapport is very important in interview settings (Gibson & Brown, 2009; Mayan, 2009; Rubin & Rubin, 2005), a certain kind of trust would be necessary to be able to ask parents about their emotional experiences of custody cases.

The interviews did, in fact, yield extremely important and interesting data for the project. Once they were completed, and a preliminary analysis of the findings was made, I met again with the CEO and the advocate, who informed me that, following their interviews, several participants had contacted her and expressed a certain satisfaction with having participated. Although the participants had initially agreed to partake in the project only if the advocate was present, they later noted, she said, some catharsis in being able to share their stories with an outsider who had taken an interest in their experiences. The advocate further reported that she had found the interviews beneficial in generating information about clients' experiences of integrating into their communities—one of the goals of the organization was, after all, helping the parents to live independently of emergency support systems and acquire some stability. The interviews, which dealt with topics like raising children, custody loss, learning to parent in light of interventions, and being able to see children again, thus addressed participants' experiences of loss, success, and transition through narration. Though I will not suggest that my position as an outsider allowed me some kind of privileged viewpoint into the participants' experiences relative to the workers of the community organization, a researcher whose background is different from the work of a community organization may provide a new perspective that complements those of pragmatic front-line workers who are restricted by financial and time constraints.

The Space of the Interview

The space of the interview was indicative, more than any other part of the collaboration, of a synthesis of information between researcher, participants, and the advocate. It was therefore also a space for reevaluating roles and perceptions. Each interview took place at the home of the participant, for their convenience and comfort. This was, however, a "practical rather than analytic" (Gibson & Brown, 2009, p. 97) decision, given that I could not take the potential effect of the location into consideration when scheduling interviews. While researchers and interviewers note the importance of finding a setting that affords some privacy and a low level of noise for optimal recording opportunities (Gibson & Brown, 2009, p. 97), there is also acknowledgement that such settings may not be available, or that the interference of daily life is all but inevitable (Roulston et al., 2003, pp. 648-649). In the case of my interviews, the participants were engaging in elements of a daily routine either before or during the interview, which informed the answers they gave, shaped their interactions, and helped to create the interview space itself. In what follows, I outline how antecedents to the interview, and mediating factors such as the community advocate fostered the development of a good working researcher-participant relation.

Antecedents of the Interview: How the Lives of Participants Set the Tone

The lives that the participants had led became quite apparent during each interview, either as a result of questions and conversations, or owing to the physical space of the interview in which the participants lived. It was evident that the levels of government, community, and family support they received contributed to a certain level of stability in their lives, which allowed the participants to reflect on their earlier circumstances and achievements. In this study, the particular effects of the participants' family situations, current living arrangements, and past experiences with government and legal institutions dictated their perceptions of, and reactions to the interview process.

The participants' homes were invariably a glimpse into the lives they wanted portrayed in the project: All had lived either transient lifestyles or in a group home, and their ability to live independently, pay rent and keep house served as a testament against stigmas of the incapability of the disabled. They also provided familiarity and comfort to the participants, however, inasmuch as they were surrounded by aspects of their lives and lifestyles. At Sandra and Doug's apartment, music was playing when I arrived with the advocate. She suggested it might have to be turned off during the interview, though I later learned that the couple liked noise in their home, and listened to music or the television in the background often. The silence may thus have contributed to some of the initial awkwardness of the interview, given that, while the space became quiet and ostensibly conducive to discussion, it was also not normal for the participants.

Similarly at Stephanie's house, the television was on because her favourite soap opera aired at the same time as the interview. She did not turn it off, but rather put the TV on mute so as to be able to follow the story while answering questions. Rachel's daughter had likewise been watching a show that ended when her interview began, and, though the TV was off, there were other noises to be heard throughout the apartment. In spite of the distracting nature of atmospheres in the participants' homes, diversions provided means to begin casual conversations. Stephanie had an interactive kitten which made its rounds to each of the visitors; Sandra and Doug had a photograph of their son which they proudly showed off on the bookshelf next to the stereo; Rachel's daughter wandered in and out of the living room where the interview was held, and her toys were scattered throughout the apartment. Daily life, in short, was in full-swing prior to and during the interviews, meaning that conversation and engagement between researcher and participants was dependent on what was already going on.

The presence of family members at Rachel's interview further informed her responses in the process, as supportive players, or even, in the case of her boyfriend who did not participate in the interview, as examples of her now-successful family life. Rachel had previously stated that the removal of her first child, who was six at the time of the interview, was apparently the result of negligence:

> My place was a trash, there was like, it was just disgraceful, so she [the social worker] warned me, and the guy that I was seeing um, she told me not to go around him, to go near him, and he slept at my place, and they found out. It was at a hotel. And then, they took him [Rachel's son].

Rachel believed that she had not been a capable parent in the beginning: "The reason why [her son] got apprehended because I neglected him". As the advocate noted, "at that time, you didn't really have an understanding, developmentally, what they [children] needed… You didn't know, with your first child. You didn't have support to help you understand that. Got a different view of it now." With her nine-month-old daughter, however, Rachel had, according to the advocate, more support through funding and housing. Equally importantly, "she has a better guy in her life! And he's got a great family."

In other cases, family members did not attend the interview itself, but visited the participants just prior to my arrival and thus affected how the participants perceived the process. Doug and Sandra's families had left soon before our scheduled interview, and it became apparent throughout our conversation that they may have been concerned about the couple participating. Doug mentioned, to the advocate, that "they had got it all wrong" and that he tried to explain what was going to happen "the way you [the advocate] explained it to us." A visit from family members, who he characterized as overly protective, just prior to the interview likely heightened the salience of his position amongst family members and the ill-treatment they wanted to protect

him from. Thus for Doug, the interview represented a forum to prove himself and his competencies rather than remain sheltered, in order to express concerns and problems he had encountered. He had to be very certain that the situation was safe, however, which the advocate assured him of. Although he was very reticent at the beginning, he gradually became more talkative and genial, asking me just before the end of the interview, "are there any more stories you want to hear?"

Transcending the gap between friendly conversation or "grand tour" questions of a parent's life activities (Miller & Crabtree, 2004), and narrating a difficult personal experience, thus depended heavily on the context of the situation. Elements of the participants' lives that were immediately obvious or accessible to memory based on surroundings or people doubtless shaped the way participants answered questions or conversed with the researcher and advocate. Developing a certain level of trust, in which such stories could be related, however, required the help and mediation of the advocate.

Mediators: Building Trust in the Interview

There is no doubt that initially, I relied on the advocate's presence to help facilitate rapport between the participants and myself. At least three of the participants were noticeably apprehensive at the beginning of their interview: When I met Sandra and Doug for the first time in their apartment, Sandra was quiet and reserved, while Doug, with arms crossed, made it clear through non-verbal cues that he was not going to be taken advantage of. While Stephanie appeared more affable at her interview, she was also quiet, giving one-word answers and seemed a little unsure about what was expected of her at first: When I asked her at the very beginning of the interview to "tell me a little bit about yourself", she was quiet momentarily; the advocate then suggested "you could tell her, kinda, how many kids you have, what's going on with them…" as a reassuring prompt. Rachel was more forthcoming about her story, having spoken at a conference and been interviewed on other occasions. She therefore provided me immediately with a brief description of some of the experiences and events she considered important to the interview. In all cases, however, arriving at the participants' homes accompanied by a person who was familiar with the participants' stories seemed to provide a kind of reassurance that neither the participants nor the researcher would be entirely isolated from the other during the course of the interview.

This sense was heightened on arrival at Rachel's apartment, given the presence of her aunt, boyfriend, and nine-month-old daughter at home. Having family members at the interview increased the salience of building rapport: While rapport is an important element of the interview, the level of disclosure it may bring is also of concern to researchers, inasmuch as there could be a risk in participants revealing or discussing more than they might normally have disclosed to a person with whom they are not close (Dickson-Swift, James, Kippen, & Liamputtong, 2007, p. 331). Although Rachel's boyfriend was not present in the interview setting itself, her aunt remained in the living room—she did not speak during the interview, but her presence forced me to consider both whether Rachel might think the questions I was asking were too personal, as well as whether her aunt would disapprove of the research project or not. Though no issues arose (my interview guides had all been carefully revised and vetted), working with an advocate before the interviews ensured that conversation proceeded along an appropriate course that accounted for the sensitivity of the situation.

The importance of rapport was particularly evident when interviewing Doug, who had agreed to do the interview, albeit with reservations. While he and Sandra began the interview giving short answers that required prompts, we ended with what could have been called a conversation. An

obvious turning point occurred half way through the interview, when the advocate mentioned the custody battle for their son Matthew immediately after he was born. Doug shook his head and said he did not want to talk about it—less, however, because of the presence of an unfamiliar researcher, but rather, as Doug said, "it just pisses me off so much I still get mad about it." The advocate then asked if Doug and Sandra would mind if she gave me details of their son's apprehension, after which they provided feedback and their opinions of the experience and how it had affected their lives.

My position as a researcher, then, was never fixed as an ultimate authority or even, on the opposite end, a democratizing co-constructor of accounts, given the particular kinds of stories participants seemed to want, unknowingly or not, to share. This was facilitated by a reciprocal relationship between advocate and researcher. On the one hand, the advocate represented a figure the participants felt they could confide in because she was familiar with the details of their cases; on the other was a researcher, who was not directly involved in the participants' cases and yet still empathetic (Dickson-Swift et al., 2009, p. 65) in the approach to the interview. This set the tone for an interview that was not directly concerned with the details of participants' cases on a legal or bureaucratic level, but how such interventions had affected their lives and how they felt about them.

Outcomes: Catharsis and the Narration of Disability

Even though the interviews were at no point concerned with assessing the suitability of the participants as parents, the impact of the legal and bureaucratic interventions on the participants' lives was certainly noticeable in the way they discussed their histories. I stated at the beginning of the interviews that I was interested in how the parents felt about the process rather than what they had been told by officials and social workers about their parenting, and that they would not be evaluated on those bases. It was clear nonetheless that the participants had internalized a level of legal discourse about their parenting, inasmuch as each parent claimed they had not been appropriate parents at the time of the children's apprehension, and that parenting courses and community group support were greatly beneficial in developing their abilities.

In talking about why her children had been removed, Stephanie explained: "I know that's because the choices that I make. The choices of people I decide to hang out with, the choices of people that I've decided to date, stuff like that." For her, taking mandatory parenting courses was beneficial in becoming a parent. "I don't mind doing the parenting programs 'cause it never hurts to learn something new," she noted, adding that one can learn "…how to discipline properly. Uhh, how to manage or deal with my three-year-old on a better uh, scale." Doug and Sandra, and Rachel, similarly mentioned the advantages of parenting classes with regard to learning how to maintain a home suitable for children.

However, the parents also expressed some frustration with the handling of their cases, and their treatment by caseworkers. Two of the participants began by explaining their current situations in terms of the number of children they had and had lost custody of. Further exploration into how they felt about intervention, however, was prefaced by saying "uh, to be honest, I hate it" or "that makes me actually mad".

When I asked Stephanie about her experiences with her caseworker, for example, she indicated some instances of disagreement between the two of them over whether her daughter should be on a certain kind of medication: "I'm not a dumb mum by any means. Usually if I says something's wrong with my kid, then, nine times out of ten there's something wrong." In describing work with another caseworker which had been easier for her, Stephanie noted that she "had been

switched to her [the worker with whom she was having problems]". After a pause, however, she added, "I… don't like her." Probing the situation further revealed a moment of catharsis for Stephanie:

> I've asked to be switched, and, it has not been done yet. So, I asked for it to be, I asked for the switch to be made way back in September, and that was even before my kids were taken. And, it still hadn't been switched. I just get told that, I only want to switch because I don't like what the worker's telling me. And, that's not the case at all… If you can't work with them, you ain't gonna get anywhere. And, and really I don't care who they are, if you can't get along with them, you ain't gonna get nowhere… Because, because you're just gonna listen to what they say, but then as soon as they're gone, you're not gonna do what they say.

Although Stephanie believed she had made mistakes in the past with parenting, she did not think they necessarily precluded her from understanding what her child needed. We never discussed disability explicitly in the interview, and as a result, the interview space became a place where she could defend some of the inclinations that her caseworker had dismissed, and address many of the social constraints (usually associated with a disability) that she had nonetheless been able to deal with.

Rachel related similar concerns about the handling of her case and her son in state care, who required treatment for the same condition that Stephanie's daughter had:

> Well they're trying to say, the worker's trying to say that if he was ten years old then she would be concerned. Right? But because he's only six years old there's still time for him to grow out of it, right? And, if he, honestly, I don't think he's gonna grow out of it, I think he's just gettin' worse. By my experience with him. Um, yeah. As every year, he's getting worse and worse and worse, so… I don't know what the government, like, is gonna do, but they can't find the adoption home that's suitable for him.

Stephanie and Rachel thus created a space where, in the presence of a trusted advocate, they were able to express frustrations to an outsider by demonstrating capabilities or knowledge that they felt had been overlooked by their caseworkers.

Taking into account the presence of someone trusted by the participants and someone with whom they are unfamiliar is important: Participants may elaborate experiences in emotional detail, or tell a richer story in order to illustrate important aspects to unfamiliar outsiders. As a consequence, the information they divulge, or the way they go about narrating their stories, may provide new insight to a known advocate or member of the community who is concerned with their cases on an empathetic, but also pragmatic basis. How stories are told to an organization worker who may have many cases to review, according to certain time lines and with limited resources, invariably differs from the way they are told when one of the only questions posed is, "tell me about your experiences." Thus while researchers and workers with organizations can partner to generate research on a population based on the assumption that the organization is familiar with the members of a population, conversations between researchers and participants have the potential to yield new perspectives for the benefit of workers and research in general.

Conclusion

While this pilot study certainly does not provide a wide-ranging description of the ways in which disadvantaged or vulnerable populations will respond to the presence of a researcher, it does raise questions about the representation of the developmentally disabled, and a possible avenue for rectification. Moreover, the study is a possible indication of the interest of some members of vulnerable populations in participating in research, as active subjects who are given the opportunity to do more than divulge requested information. This has consequences for further investigations into the importance of university-community collaboration with vulnerable or hard-to-reach populations, given the potential understanding by the community about the benefits of research for its members. However, further study in this area is certainly needed.

Although the difficulties of working with a population as an outsider, and the beneficial mitigating effects of partnering with community organizations to conduct research have been noted, an important dynamic exists in the researcher's externality that can be valuable for the promotion of health equity for the disabled. The importance of sharing stories in order to hear the voices of the developmentally disabled was critical for the organization I worked with, as a means of raising hidden issues to the surface and addressing unknown or unacknowledged problems. Consequently, a major goal for the organization, in partnering with the university, was the chance for someone unfamiliar with the immediate problems or experiences of disabled parents to hear and record their stories. The role of external researchers in this process is, consequently, an important one, which can range from extending empathy to individuals who may feel isolated as members of a vulnerable population by recording their narratives; to promoting and undertaking major research programs that can help improve social conditions. The researcher, however, is very much dependent on community organizations to be able to contact and build trust with participants. As is well known, researchers' encounters with hard-to-reach populations in the absence of local knowledge and help can be difficult, and it is certainly not the case that an outsider's interest in a population promotes immediate empowerment or strength. Collaboration with community organizations is therefore paramount to such investigations, given its potential to shift researcher-participant relations in a way that benefits not only the research, but the participants themselves.

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