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### Cover Page Footnote

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# It's Like I Have an Advantage in All This: Experiences of Advocacy by Parents of Children with Disabilities from Professional Backgrounds

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*Supports and services for children with disabilities are not distributed equitably. There are disparities in access to and quality of services for children with disabilities from low-income and ethnic minority groups. There are likely many contributors to these disparities, but one factor may be barriers to access that require parents to advocate to obtain services for their children. This qualitative study explores advocacy experiences of parents of children with disabilities (n = 40) who have a high level of education and/or professional achievement. Parents described relying heavily on their professional and educational backgrounds in advocacy, and some commented upon the “advantage” they had in accessing services. In the context of an international shift in developmental services policy towards self-determination and privatization, parents and guardians will play an even larger role in decision-making about services with their dependents with disabilities. The findings of this study suggest that support and training for parents and guardians*

*as they navigate this new policy environment is especially critical given the role of parental knowledge and skills in advocacy activities.*

*Keywords: caregiving, inequality, parenting, disability, advocacy, qualitative research*

Over the past several decades, social welfare policy and practice in the area of disability has been increasingly focused on consumer and family member empowerment. One of the biggest changes is in the financing and delivery of support services for individuals with disabilities. In the past, services were typically reviewed, managed, and approved by a case manager. Over the past two decades, in several countries, including Australia, Canada, England, Sweden, Germany, and the United States, families and consumers are being offered the opportunity to manage disability services on their own (Piccenna, Chee, Lewis, Gruen, & Bragge, 2015). In the United States, 10% of individuals with disabilities in 15 states receive services under state policies that support self-directed plans (United Cerebral Palsy, 2019). Other U.S. States, including California, are initiating self-determination plans (California State Department of Developmental Services, 2015). In Australia, self-directed services are a key feature of the National Disability Insurance Scheme (NDIS) policy (Victorian Government Department of Human Services, 2017). Many of these new plans, such as Australia's NDIS and California's self-determination option, are specifically for adults and children with disabilities. When the consumer with a disability is a child, services are organized by a parent or legal guardian on the child's behalf (Australian Department of Human Services, 2019; California State Department of Developmental Services, 2015).

The existing service systems often put parents and providers in adversarial relationships, whereby parents of children with disabilities feel they must "fight for services" and that "screaming loudly" is necessary to access timely, appropriate, and relevant therapies, services, and supports for their children (Ryan & Quinlan, 2018, p. 205). Societal and systemic barriers contribute to the difficulties in accessing services for children with disabilities. Institutionalized discrimination, stigma, and

outdated attitudes about people with disabilities affect consumers, family members, and providers and inhibit the well-being and meaningful participation of people with disabilities in our society (Ditchman, Kosyluk, Lee, & Jones, 2016; Hatzenbuehler, Phelan, & Link, 2013; World Health Organization, 2015). Other barriers include resource limitations, fragmentation in services, lack of cultural competency, and need for training in specific disabilities and the services that may be most relevant and helpful (Ditchman et al., 2016; Hatzenbuehler et al., 2013; World Health Organization, 2015).

Within this complex service context, as disability policies shift towards self-determination, it may be even more important for parents and caregivers to be effective advocates for their loved ones. The lack of an assigned caseworker with experience in navigating disability services increases consumer and family responsibility for managing services, and thus presents opportunities and challenges for families. Families may be able to select services that they feel best meet their children's needs, but they need to be aware of the services available, laws and regulations guiding these services, and means to address problems that may arise in accessing or using services (Purcal, Fisher, & Meltzer, 2016). There is a potential for this shift towards self-determination and privatization to exacerbate already existing disparities in access to services for children with disabilities, as families cannot request services that they do not know exist and cannot demand enforcement of legal requirements of which they may be unaware. There are likely many contributors to these disparities, but one factor may be barriers to access that require parents to advocate to obtain services for their children. The current study explores advocacy experiences in parents of children with disabilities ( $n = 40$ ) who have a high level of education and/or professional achievement.

## Parental Advocacy and Service Disparities

Over the past decade, an emerging research base, briefly summarized here, has begun to document the need for parents to advocate on behalf of their children, parents' perceptions of their role as advocates, the activities parents engage in, the knowledge and skills needed for advocacy, and training programs to support parents in their advocacy work. Parents of

children with disabilities typically engage in advocacy throughout their child's lifespan, from infancy through adulthood, with greater need for advocacy efforts during times of transition, for example, from early childhood to school-based services (Burke, Patton, & Lee, 2016b). Parents believe that advocacy is necessary and supports their active coping with the challenges of having a child with a disability, but parents also describe it as burdensome and exhausting (Green, 2007; Wang, Mannan, Poston, Turnbull, & Summers, 2004; Wright & Taylor, 2014).

Common settings for advocacy include educational institutions, medical centers, social services, and social media (Wright & Taylor, 2014). Parents may have more experience with, and feel more effective in, advocating at the micro level in schools, clinics, and social services agencies rather than at the macro level through community and political organizing (Wright & Taylor, 2014). Advocacy activities include raising awareness about their child's disability, educating themselves on their child's disability, learning their rights, educating others, and working to access educational, social, and medical services (Chadwick et al., 2012; Wright & Taylor, 2014).

There is limited research on the experiences of low-income and ethnic minority families who have children with disabilities (Grossman & Magaña, 2016; Vanegas & Abdelrahim, 2016). Given that access to educational and social services may depend on a parent or caregiver's awareness of the services available and advocacy on behalf of their child, concerns have been raised about disparities in provision of services for families with linguistic, cultural, educational, and/or socioeconomic barriers to engaging in advocacy (Cohen, 2013). The existing research suggests that supports and services for children with disabilities are not distributed equitably. For example, there are disparities in access to services for children with autism from low-income, African American, and Latinx families (Liptak et al., 2008). (Latinx is a gender neutral alternative for Latino/a that is growing in usage [Steinmetz, 2018].) In California, racial and ethnic minority clients of Regional Centers that serve individuals with developmental disabilities are less likely to receive services than white clients (Harrington & Kang, 2008, 2016).

Several factors may contribute to these disparities. The well-documented disparities in access and quality of education, health care, and social services that exist for families of color

may be compounded by a child's disability, such that racial and ethnic minority parents have an even greater need to advocate on behalf of their children. At the same time, an embedded advocacy expectation may present an additional barrier for some ethnic/minority families. Parents may avoid advocacy as they feel they should defer to professional opinion (Kalyanpur, Harry, & Skrtic, 2000). Parents may also appreciate the services that are offered and be reluctant to be critical. Others may fear that teachers and other providers will retaliate if a parent complains (Chadwick et al., 2012). For very low-income families, frequent changes in contact information may inhibit follow-up (Khowaja, Hazzard, & Robins, 2015). These barriers to advocacy may present additional challenges for culturally and linguistically diverse families, because of gaps in the resources and training of providers to serve families effectively (Harry, 2008; Williams, Perrigo, Banda, Matic, & Goldfarb, 2013).

Parent training courses in the knowledge and skills required for advocacy have been developed and offered to various parent groups, including Latinx parents of children with autism (Burke, Magaña, Garcia, & Mello, 2016a). Training may also have a specific topical focus, such as advocacy in educational settings (Shepherd & Kervick, 2015) or macro-level advocacy (Gray, Duenas, & Daar Watson, 2015; Schuh, Hagner, Dillon, & Dixon, 2017). Emerging evidence suggests that these types of trainings help parents to feel more empowered and effective as advocates (Burke, 2013, 2016; Burke et al., 2016a; Gray et al., 2015). The trainings also appear to be beneficial to people across diverse socioeconomic, race, and gender backgrounds (Schuh, Hagner, Dillon, & Dixon, 2017).

In summary, the literature suggests that advocacy is a critical aspect of parenting a child with a disability. It also indicates that disparities in access to services exist for low-income and racial and ethnic minority children with disabilities, and that parent training courses may help to augment parents' advocacy skills. However, there is a need for more research on the specific knowledge and skills parent advocates use in accessing services to help understand these disparities and to develop policies and programs that can address inequalities in care. This review of the literature led us to the following research questions:

1. What knowledge and skills do parents use in advocating for their children with disabilities?
2. What personal characteristics or advocacy styles do parents employ?
3. What is the impact of these advocacy efforts?

## Method

This descriptive, exploratory study followed Miles and Huberman's (1994) three-step process for qualitative research, which involves data reduction, data display, and development and verification of conclusions. We began with a conceptual framework (Lofland & Lofland, 1995) informed by the literature, practice experience, and discussions with key informants to narrow our focus. This conceptual framework encompassed the issues highlighted in our literature review, including themes related to the need for advocacy, goals of advocacy, and the settings in which advocacy occurs. The second author's practice experience and research in global child advocacy (Wright & Jaffe, 2013), which has included training parents of children with disabilities to advocate for their children in Australia, also contributed to our conceptual framework. The intention was to use the conceptual framework as a starting place, with an openness to being surprised by our data and revising our preliminary understandings through the process of data collection, preliminary analysis, and deeper analysis.

The study was also informed by the first author's experiences as a parent of a child with a disability. One of the graduate student researchers who served as an interviewer and assisted in the initial stages of analysis also identified as a parent of a child with a disability, thus the initial six-member research team included two parents of children with disabilities. The parent voice was part of all research decisions from design through analysis and writing, and these parent-researchers were able to gain access to other parents through groups with which they had connections. To avoid any conflicts of interest, if either parent-researcher had a prior connection to a potential participant for the study, she re-assigned her interview and preliminary analysis of that data to another member of the team. The strengths of the inclusion of parents of children with disabilities on the research team reflect those described in the



literature on reflexivity, including access to participant populations, participant willingness to share personal information, and the meanings parents bring to the research, from design through analysis (Berger, 2015).

### *Participants*

Adult parents ( $n = 40$ ) of one or more children with a disability were invited to participate in the study. The majority ( $n = 35$ ) of participants were White/European American. Eighty percent of the participants reported that they were married ( $n = 32$ ). The sample was highly educated, with most of the participants ( $n = 35$ ) having completed either an Associate's degree or some college. Furthermore, 75% ( $n = 30$ ) of participants had completed at least a Bachelor's degree, while more than a third ( $n = 15$ ) had obtained their Master's degree or higher.

Nearly one quarter ( $n = 9$ ) of the sample was employed in either K-12 education or social services; two thirds of these parents stated that their experiences with their own children influenced their decisions to pursue their chosen careers, with six individuals working directly in social services related to disability ( $n = 3$ ) or special education ( $n = 3$ ). Several other participants ( $n = 4$ ) reported careers in higher education or research ( $n = 3$ ) and one in healthcare. Eleven of the participants stated that they were employed but did not specify their profession. Forty percent of the sample ( $n = 16$ ) were either unemployed or full-time caregivers, but this includes a retired parent and a parent who volunteered full-time to run a small non-profit. Many of these full-time caregivers had been employed in professional occupations prior to having a child with a disability.

Most of the families ( $n = 35$ ) had three or fewer children, and over 87% ( $n = 37$ ) reported having one child with a disability. However, several of the families ( $n = 5$ ) had multiple children with disabilities, while four participants reported larger family sizes (four or more children). The participants described their children as having a wide range of disabilities including intellectual, developmental, neurological, and physical disabilities, as well as mental health needs, and injury-related conditions. The most commonly cited diagnoses were autism and autism spectrum disorder (including Asperger's syndrome), with nearly one third of participants ( $n = 13$ ) reporting these in at least

one of their children. The age of the children ranged from infancy through adulthood, with 10% being ages 0–5, 19% ages 6–10, 17% ages 11–14, 20% ages 15–18, 13% ages 19–25, and 20% over age 25.

### *Recruitment*

The study was reviewed and determined to be exempt by the Institutional Review Boards of two public universities in California employing each of the lead authors in October 2012. Participants were recruited from a large sample of parents of children with disabilities who completed an online survey ( $n = 304$ ) for a previous study (citation removed for peer review) intended to gather information about parental advocacy experiences and perceived effectiveness of advocacy. The survey and interviews were completed in 2012–2013. The survey participants were initially recruited via social media and email listservs for parents of children with disabilities; the response rate is unknown, given that the initial survey announcements were forwarded to various individuals and groups by survey participants themselves and other interested individuals. Our sampling goal was 100 participants. The final sample included over 300 parents from 38 states, as well as six other countries.

The following question at the end of the survey was used to invite participants to share their experiences in an interview:

Thank you so much for taking the time to participate in this study. We would like to invite you to participate in a phone or in-person interview to discuss your experiences in more detail. The interview would take approximately one hour. If you are interested in this optional, additional portion of the study, please click here.

Parents were offered a \$15 gift card as an incentive to complete the interviews. Departmental funds available to the lead author were used to pay for the participant stipends. The initial survey from which the interview sample was drawn was anonymous. When parents volunteered to participate in a follow-up interview, they were taken to a new online web form (not connected to their survey responses) that requested their contact details. This information was only used to schedule and complete the

interview; interview notes and transcripts were immediately de-identified once the interview was complete. Nearly 100 parents ( $n = 98$ ) indicated interest in being interviewed, but many of these did not respond to follow-up attempts, thus the final interview sample included 40 parents, approximately 13% of those who participated in the initial survey. The sample size was driven in part by participant interest (i.e., more parents indicated interest than we anticipated, suggesting that many parents had experiences they wished to share), as well as a desire to have a sample that included parents of children of varying ages, disabilities, and regions.

### *Data Collection*

Parents participated in semi-structured interviews regarding their family situations, advocacy activities, and reflections on advocacy-related successes and challenges. The 30-60-minute telephone interviews were recorded and professionally transcribed. Given that a national sample was used, telephone interviews were necessary as our study budget did not permit travel. A team of four graduate student research assistants in Social Work completed the interviews after participating in approximately six hours of training in ethics, confidentiality, and interviewing. We also trained the team in the importance of making participants feel comfortable and building rapport through using an opening script. This script provided information on the purpose of the study and assurance that participant identities would be kept confidential. As social work students, they were already skilled in engaging with a wide variety of people in discussion of sensitive topics. The training also included completion of audio-recorded mock interviews, which were reviewed by the first author.

The two lead researchers developed the interview guide based on a preliminary analysis of data from the survey noted above. The second author piloted the interview guide with one parent of a child with a disability. The interview was semi-structured and included nine broad questions with probes that were asked only if the participant did not address the sub-topics under the broad question. For example, the first question in the survey was, "Tell me about your family." The probes were:

- How many adults are in the family?
- How are the children taken care of throughout the day?
- How many children do you have?
- What are the ages of your children?
- How many of your children have special needs?

Subsequent questions asked the parents to describe themselves, their children's strengths and challenges, a successful experience of advocacy, an experience of advocacy that did not go as well as expected, and supporters and facilitators of advocacy efforts.

### *Analysis*

A research team consisting of the two lead researchers and two graduate student research assistants developed a codebook based on the interview guide, and then revised the preliminary codebook based on emerging findings from review of the transcripts. Initial index codes included broad categories such as advocacy activities, advocacy goals, coping, perceived challenges, emotions and reflections, technical expertise, personal characteristics, and support or lack of support.

Two graduate research assistants who had completed a course in quantitative and qualitative analysis and a two-hour training in coding specifically for this study served as the primary coders. Using Dedoose qualitative online software, the codebook was applied, tested, and revised in an iterative process until a .70 kappa score of inter-rater agreement was achieved between these two coders. The lead researchers then identified the major themes and relationships among concepts through an axial and selective coding process. For this analysis, we focused on stories of successful advocacy efforts and what parents said in response to questions about what contributed to their ability to advocate effectively. As we worked through our analysis, we reached the point of saturation, at which time the themes and concepts appeared to be exhausted (Saunders et al., 2018).

### *Trustworthiness*

Efforts to ensure the reliability and validity of the analysis included peer debriefing and negative case analysis (Miles & Huberman, 1994). Peer debriefing was completed through

frequent discussions among members of the research team about coding and preliminary findings. Negative case analysis involved looking for cases that did not adhere to patterns initially identified, and then revising these preliminary patterns to better reflect the data. Member checking was not feasible for this study, but as noted above, the research team included two parents of children with disabilities who provided ongoing feedback based on their lived experiences.

## Findings

Parents attributed much of their advocacy successes to the knowledge and skills they employed as well as their advocacy style and personal characteristics. We also explored the impact of advocacy in terms of cumulative gains or losses and career trajectories.

### *Knowledge and Skills*

The knowledge and skills parents utilized in advocating for their children were categorized as follows: (a) Knowledge of laws, policies, and norms; (b) Knowledge and skills acquired through professional and formal educational experiences; (c) Knowledge specific to their child's disability.

*Knowledge of laws, policies, and norms.* In sharing their advocacy stories, parents described detailed and complex knowledge of special education laws and policies, curricular issues, district-specific policies, medical insurance guidelines, and social service programs. For example, one parent stated:

I felt I was in control of that IEP [Individualized Education Plan]. I knew exactly...this was the first time I can actually say to you, in all the years, I knew my daughter's present levels, I knew what she needed, I knew where she's going next year, I knew what her goals should be, I knew...and I actually understood everything single page of that IEP.

Many parents felt their knowledge of specific educational policies and the way to state their requests using policy-oriented language was critical to their successes in advocacy. For example, one parent commented:

So for my elder son they wanted to discontinue his services in seventh grade and I had the knowledge to know to ask for a “private evaluation at public expense,” but if you don’t ask for it that way, you’re probably not getting it. So, it was, okay, flip to the page that has that, copy the words exactly, tell them you want a new IEP and they can’t change anything because you’ve requested it until they respond to your request. At the time, the people in the room were, “Oh, no, we’re not giving him speech therapy anymore. We’re discontinuing this and we’ll look in to this.” I said, ‘No, actually you’re not.’ I said, “Legally you’re required to keep everything the same until you address my concern.” So, I got a call the next day saying, “Oh, yeah, I was right, his speech would stay in place.”

*Knowledge and skills acquired through professional and formal educational experiences.* Many of the parents in our sample had professional backgrounds in fields such as law, social work, education, medicine, science, writing, and nursing. Parents described drawing on this knowledge in their advocacy work. Nearly all of the parents who specified their fields cited them as contributing to their effectiveness as parents of children with disabilities, noting that their vocations helped enhance their advocacy skills as well their medical, technical, and legal knowledge. The specific knowledge and skills parents described included:

- Knowledge of child development
- Policies and funding
- Terminology
- Effective communication via email, letters, and phone calls
- Networking
- Knowledge of community resources
- Leadership
- Argumentation
- Public speaking
- Marketing

The following examples illustrate how parents felt their skills and knowledge informed their advocacy work. This parent described how her and her husband’s backgrounds in policy and law were valuable:

I would be lying to you if I didn't say that the fact that my husband and I are well educated is a huge factor. He is an attorney. We both have Master's degrees in public policy...We both work for the Federal government so we understand how bureaucracies work. We understand how to lobby and advocate, how to work the system, and call people and write letters and how to write good letters and all that stuff.

Another parent used her social work background to inform her advocacy work:

I've been fortunate that I have private insurance and I help people in the community so I can ask about different providers, but, I mean, again, it's like I have an advantage in all this being a social worker with my skills and connections and then sometimes I think and go, "Oh, my God, what if I wasn't a social worker?"

Parents also cited professional experience in fields that were not clearly related to disability. For example, one parent learned problem-solving skills through her astrophysics training: "I think my education background has helped a lot. I have a degree in astrophysics, so I'm used to learning complicated stuff and trying to apply it to different problems. I'm a good problem solver." Another parent who is a professional writer describes how her skills support her advocacy:

It just struck me that my whole professional career up to this point in some ways was a preparation for me to be an advocate. My professional background is as an editor and writer and marketing communications person. So, whether it's learning new material or getting the material out to people in a convincing way, it's really all about advocacy.

*Knowledge specific to their child's disability.* Parents described needing a deep knowledge of their child's condition, including research on the condition, evidence-based interventions, and potential long-term outcomes. Parents often felt their knowledge exceeded that of many professionals with whom they interacted and felt frustrated by the need to educate these experts. Parents' knowledge of their child's disability was influential in obtaining a diagnosis, which is essential for access to some services:

Interviewer: How did you first learn of your son's special needs?

Parent: How did I learn of them? I suspected them. I'm a physician myself so he was actually the first patient I actually saw with autism and I took him in requesting a developmental screening for him about sixteen to seventeen months of age when he stopped playing joint attention games with us on the changing table. That was really the first red flag for me.

Parents' knowledge also informed the types of interventions they felt were appropriate for their child. This was particularly true for parents whose children had rare conditions:

And then in terms of his medical treatment, it's kind of the same thing. You have to be, you have to learn how to advocate for what's best for him by doing the research on what are the latest treatments, what's going on in the world of treatment, not just for epilepsy, but for his underlying disorder to [disorder name removed for confidentiality], because it's a rare disease. They aren't going to be able to stay informed on all aspects of it and be ready in the event that his disease takes a turn in that particular direction. I know what the latest research is, and I can say, "We're doing this," to a point where I researched and eventually we decided for him to participate in a clinical trial in a research experimental trial. And that you can't do, you can't do that without doing your homework and being the advocate, because the first doctors say, "Well, that's not the way to go," and if you don't do your research and stand up and say, "No, we've looked at it and we're willing to go there, we've evaluated the risk." I guess that's my byline for any kind of advocacy is you have to do your research and evaluate the cost benefit of each decision and then go with it and stick with it, if it's the best thing for your child.

### *Advocacy Styles and Personal Characteristics*

In addition to knowledge and skills, parents often remarked on personal characteristics that they felt contributed to their advocacy efforts. The most frequently noted self-identified personal characteristics include determination, persistence, stubbornness, and tenaciousness. These characteristics were discussed by nearly all of the parents. For example, one parent stated:



I'm the squeaky wheel. I'm the person that just never goes away. I'm the person that calls back again and again and again. I'm the person that just won't take no for an answer. "Okay, who else do I need to talk to? What other things can I try?"

Another shared, "I'm tenacious, I'm stubborn, I'm persistent, I'm very confident with research and once I set my mind to something, I'm hard to persuade different. So, I guess my tenacity and my persistence would be my character strength."

The overwhelming majority of the parents also expressed deep dedication to their children. This dedication was occasionally described in cultural or spiritual terms, as with one parent who commented:

I would say that I guess what it comes down to is cultural and spiritual practices. Because in Lakota culture the word for children, it means "the holy ones." That was always a guiding principle for me as well. Because we are taught that our children are sacred beings. They're holy and that's how you treat them. Even when they're having a temper tantrum or even when you're changing dirty diapers for the millionth time. This is a sacred being before you. So that was always at the top of my mind. That's why I expect my child to be respected, to be valued for the person that he is. That's why I think that has focused my efforts; the things that I've done.

Parents described using distinct individual personal characteristics in their advocacy work and felt those personal characteristics contributed to their success. The quotations below indicate how very different advocacy styles can be effective. This parent tries to be "cooperative" and "a team player:"

So, I'm not...it's not my style to cause trouble for the school. I'm not comfortable doing that, I'd much rather be a good citizen. I'd much rather say, "Yes" almost all the time, so that once in a while I can say, "No" and we can stick. I'd rather be known in that way. I'm not a pushover. I do not want to be known as a pushover, but I want to be known as cooperative. I want to be known as constructive and a team player and that way when I need to say, "No", they won't just roll their eyes. So, that's a style choice that advocates need to make.

How do I get her, how do I move through world, that's just my style, it's not everybody's style.

In contrast, other parents described themselves as very assertive or even aggressive at times: "Okay. I would say personality-wise, I'm from New York. That has helped, to be aggressive when I need to."

A few parents described utilizing a team approach, relying on complementary characteristics between themselves and their partners or spouses, where one parent is the more cooperative one, and the other takes on a more assertive role.

### *Impact of Advocacy*

Many parents described advocacy as exhausting yet felt proud of the outcomes they were able to achieve. They felt their advocacy successes were cumulative, with impacts on their children's lives as well as their own well-being. The next two quotations provide contrasting perspectives on successful advocacy versus missed advocacy opportunities. A parent who shared a successful advocacy experience commented on how it was "worth it" despite the personal toll it took on her:

The whole thing with getting her in the school and out of that bad environment—I was exhausted; it was emotionally very taxing which was a little bit of a surprise. I didn't expect to be so strongly affected by that. I almost felt like I needed counseling after going through it...there is a definite emotional pull and tact that it takes, but it's all worth it and you get yourself back together, you find your support. Everyone sees that what you did was the right thing and you've gained more credibility in everyone's eyes, which really feels good... and having friends and family that support you helps restore you too.

A parent who missed an advocacy opportunity commented on feelings of rejection and continuing disconnection from her spiritual community:

But my real failure was that my feelings were so badly hurt and I did not go to somebody over his head and say, "Hey, are you going to back him up or is this really what the church

means to do?" I just walked away and hid, because I just felt so rejected. I'm better at facing that on my own behalf than on my child's behalf. I still haven't done anything about it and that was three years ago, we just don't go to church, which is terrible...

In the successful advocacy experience, the parent gains support and "credibility." In the second, the family becomes more isolated.

An additional sub-theme in this area is how the experience of advocating for their child shaped the career paths of some parents. Though most parents described using knowledge from education or work they began before having a child with a disability, a few parents commented on how the experience of having a child with a disability changed their career path or led to increased professional success. Two parents in this study started non-profit organizations to support and advocate for children with disabilities, one became a special education teacher, and another described being more effective in working with other parents at her current job in education as a result of her own parenting experiences.

## Discussion and Conclusion

Parents' knowledge reflected a sophisticated understanding of core elements of policy, including eligibility, program goals, benefits, the service delivery system, financing, and cost analysis (Chambers, 2000). The fact that parents relied heavily on their educational and professional backgrounds suggests that without strong social policies that guarantee equal access to supports and services for individuals with disabilities, gaps in services and eventual long-term outcomes may be exacerbated. This may be especially true given the potential for gains or losses to be cumulative, starting with access to early intervention services following a diagnosis at a young age. Many parents seemed to recognize this and sought to use their knowledge and skills to improve services not just for their own children, but for all children. The insights offered by this sample highlight the skills, time, and energy parents feel are required to gain access to supports and services that should be provided to all children with disabilities regardless of parental effort.

Policies emphasizing consumer and family member involvement have an embedded advocacy expectation, which assumes that families have access to information about services, rights and resources. Moreover, these policies are premised on values of equity, individual rights and freedom of choice that fit with the value orientations of middle-class professionals but may be antithetical to culturally diverse families (Kalyanpur et al., 2000). In the advocacy expectation, parents are “expected to know and understand what professionals know” (Kalyanpur et al., 2000, p. 129) and therefore parents who possess the knowledge, value orientations and confidence of professionals have a considerable advantage.

The inherent divide is cultural capital and social transmission of privilege. Cultural institutions such as schools reflect the dominant cultural and class groups. Children from these groups are socialized within the family to develop the social, cultural and linguistic competencies that enable successful navigation through the expectations of the culture. Those from non-dominant groups must acquire the knowledge and skills that come naturally to upper and middle classes (Lamont & Laureau, 1988). Laureau (2011) found in her ethnographic study, *Unequal Childhoods*, that middle class professional parents made frequent criticisms and interventions in institutions such as schools on behalf of their children. Observing these interactions, their children developed an emerging sense of empowerment and ability to see opportunities within institutional structures to get what they wanted. By contrast, working class parents expressed feelings of dependence with a sense of powerlessness regarding institutions and their children developed a sense of constraint and alienation when confronting social institutions (Laureau, 2011). The advocacy expectation contributes to a Matthew effect, defined by Merton (1968) as “the principle of cumulative advantage that operates in many systems of social stratification to produce the same result: the rich get richer at a rate that makes the poor become relatively poorer” (p. 7). In the case of disability services, parental advocacy is the key to accessing resources. The advantages already afforded to professional middle-class families enable them to use these advantages to gain more resources, thereby increasing the gap in access to resources between children in middle class and working class families.

*Study Strengths and Limitations*

Limitations of this study are the reliance on participant recall of past events and a focus solely on parents. It is likely that the other players (i.e., the child with a disability and professionals) involved in the events around which parents advocated would have a different perspective.

A strength and limitation of this study was the unintentional oversampling of parents from highly professional backgrounds who went to extraordinary lengths to advocate for their children. This happened both through selection bias (i.e., parents volunteering for a study about advocacy experiences are more likely to self-identify as parent advocates) and through the recruitment method via social media, attracting parents with access to the internet and connections to online communities for parents of children with disabilities. Though we had hoped for a more demographically diverse sample, the participants provided highly relevant and rich information for this research, and connecting with them outside of social service agencies was positive, in that for most of these parents, social media is a naturalistic setting in which they are comfortable, and through which they connect with other parents and engage in advocacy. Relevance, richness, and naturalistic settings are advantageous in qualitative sampling (Abrams, 2010).

*Policy Implications*

Having a professional background appeared related to parents' capacity and confidence to act as advocates for their children. While this was a boon to their own families, it suggests that more privileged parents may be better positioned to identify and request appropriate services for their children, which can act to reinforce inequality. Our findings suggest that there is a tension between the policy goals of self-directed services, with the promise of equal access and choice, and implementation that is mediated by parental advocacy. Differences among parental ability to advocate for their children can create distributional inequality. Indeed, research on user experiences of the National Disability Insurance Scheme national policy in Australia have identified concerns that factors "...driving inequality—household income, education, residential location and household structure—

remain critical in filtering opportunities and capacities for service users and their carers to have choice and control in accessing services" (Warr et al., 2017, p. 9).

This finding underscores the importance of policy efforts to eliminate barriers to accessing supports and services for people with disabilities. This work could include simplifying forms and procedures, translating policies into multiple languages, providing access to resource and referral agencies with skills in working with culturally and linguistically diverse families, and making policies that are transparent and written in accessible language. One example of these types of policies is the Australian federal government's an initiative to use "plain language" in legislation (Australian Government Office of Parliamentary Counsel, n.d.). Another example is in California's recent passage of a bill (AB 959, 2017) that requires Regional Centers, the state organizations responsible for managing developmental disability services, to provide clear and consistent information on their websites. The bill also requires Regional Centers to make information culturally and linguistically accessible.

Our findings suggest a need to strengthen universal screening and case-finding efforts that require schools, medical clinics, and social service agencies to seek out children who will benefit from support. In the context of self-determination policies, there is a call for highly skilled support planners who can assist adults and children with complex needs and their parents in navigating this new service environment (Collings, Dew, & Dowse, 2016).

### *Practice and Research Implications*

While engaging in this macro-level work, it is also necessary to provide micro- and mezzo-level counseling, support, and training so parents can access existing services for their children. Our research underscores the value of parent training programs such as those noted in the literature review. The programs must provide classes that are accessible to families who have work schedule, transportation, and other barriers to participation.

As children with disabilities grow into young adulthood and assume greater responsibility over their lives, their ability to self-advocate is strongly influenced by their parents, who can act as instructors, mentors and role models (Bianco,

Garrison-Wade, Tobin, & Lehmann, 2009). The ways in which young adults are supported in becoming effective self-advocates is an indirect pathway between privilege and parental advocacy that bears further investigation.

Future research is needed on the experiences of diverse families. Because of the relative affluence of this sample, we are unable to draw conclusions about the experiences of families from less advantaged communities. It is reasonable to guess that the advocacy experiences of families from other communities differ, but further study is needed to learn more about how and in what ways the experiences might diverge.

Future research is needed on the skills and knowledge low-income and under-resourced families already employ in their advocacy. This will allow parent training programs to build on existing skills. In addition to learning more about the experiences of diverse families, future research should explore inequality in access to services in more detail, comparing affluent families with those from more disadvantaged backgrounds. This could be done through a review of administrative data from large government and private non-profit social service agencies, schools, and medical clinics. This quantitative research should still include a qualitative component, because so much of the experience is subjective and involves reflection on advocacy goals, activities, and outcomes. Longitudinal research would be helpful in learning more about how advocacy experiences unfold over time.

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