Exploring the Disability Parent Community in WA: Reliance on Community in Navigating the Healthcare System for a Child with a Developmental Disability

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Why do disability parents have such a difficult time navigating the healthcare system?

How do disability parents rely on each other for support in navigating the healthcare system?

Introduction

To begin with my positionality and connection to this work, I am a pre-medical student at the University of Washington where I am majoring in Medical Anthropology and Global Health, and for a large part of my life, I have been a disability advocate and ally. My goal is to pursue developmental pediatrics, where as a future physician I will serve families who have children with various developmental disabilities. I grew up with a close family friend who was on the Autism Spectrum, and have since held close and meaningful friendships with individuals with disabilities. I identify as nondisabled, although I hold many close relationships with individuals with disabilities and their families. I also work as an in-home caregiver for these families, and as a pre-medical student, have formed connections at the University of Washington Medical Center at the Center on Human Development and Disability, as well as at Seattle Children's Hospital in the Neurodevelopment Clinic, where I have shadowed healthcare providers extensively as they serve families who have children with developmental disabilities. In my experiences with this population, listening to friends, their parents, the families I work for, and the families I have observed in clinical visits, it became apparent to me that most of these families have an extremely difficult time learning how to navigate the healthcare system for their children after receiving a diagnosis. I found that there is an incredible disconnect and lack of support at the time of diagnosis for these families, and often it is not the healthcare providers that support these families and assist in their navigation of the health system moving forward. Rather, the experience of other parents that have gone through the process of navigating the health system for their child with a developmental disability is the best resource for these newly diagnosed families.

From a medical anthropology perspective, I am particularly interested in the experience of families with children with developmental disabilities in navigating the healthcare system, specifically in Washington State. Developmental disabilities include Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, Cerebral Palsy, Down syndrome, fetal alcohol syndrome and others, and are all categorized by differences in progression through the developmental stages of one's life. Developmental disabilities can be explained as a group of lifelong conditions as a result of an impairment in physical, learning, language, or behavioral areas of development (Zablotsky et. al., 2021). The health outcomes of children with disabilities are strongly correlated with the family's ability to navigate our complex health system, so I am interested in the progression of this navigation process at the early stages, from the initial diagnosis through getting "plugged in" with the health system and the disability community. One of the more surprising observations from my experiences listening to parents has been the incredibly strong reliance on community in navigating health care; often parents say that they learned more about how to maneuver through the complex medical system only once they were connected with other disability parents, rather than from their child's healthcare providers.

When parents are told that their child has a developmental disability and receive an initial diagnosis, there is a very wide range of reactions among parents of different backgrounds. Some parents are accepting, understanding, and as a result of prior experience with people with disabilities, feel well-equipped to take on the disability parent role. The vast majority of these parents though, feel that they are thrown onto another planet, alienated from "typical" family experiences or parenting milestones, are confused about what to do next or who to seek help from, and are often lost to fend for themselves in determining what the best course of action is for their child. As someone who has many friends with disabilities, I have seen and understood the incredible importance of having well-equipped parents who believe in their child, who see their child as a person capable of success rather than a diagnosis that needs to be fixed. The ability of parents to make educated and thoughtful decisions about accessing their child's services is directly correlated with the child's ability to develop to their full potential. If this research is able to better serve parents in their healthcare decision-making for their children, it will in turn improve the lives of individuals with developmental disabilities in Washington State. By studying the power of community, this project may also serve to inspire further research into parent communities of other marginalized groups, and how to best advocate for their children in healthcare decision-making.

This research aims to understand why such a reliance exists within the disability parent community in Washington State in terms of navigating healthcare, and how the healthcare system can do a better job of supporting families who have children with developmental disabilities. This work aims to highlight the strength, reliance, and efficacy of the disability parent community in Washington State in assisting new disability parents in navigating the health system. In addition, this research examines what is missing from the healthcare system in the initial stages of navigation for these families. The findings of this project are intended to be utilized in bridging a gap between the healthcare system and the disability parent community, so that they can work more in unison to serve families with children with developmental disabilities, and most importantly, improve the lives of these children.

The research findings included in this thesis about the disability parent community and the power of community in navigating healthcare cannot be properly understood without giving backstory as to how challenging, complex, and oftentimes harmful the systems truly are. This thesis is designed to first, explain the complexity of the system and why these parents face a great challenge once they receive a diagnosis of a developmental disability. Second, I will explain the power of the disability parent community in learning how to navigate healthcare, and will propose suggestions in order to bridge the current gap between the healthcare system and the disability parent community. This research cannot be generalized; the information gathered is a direct reflection of the system in Washington State, and all of the findings are influenced by my own privilege, and the privilege of the individuals who participated in this project.

Research Questions

What is lacking in our healthcare system and in our providers' ability to connect families to services, to where families must rely so heavily on one another to navigate the health system?

Maybe more importantly, if this tight-knit social community is what works most effectively to educate new disability parents on how to navigate the health system, then how can our healthcare system aid in connecting families to this community early on and post-diagnosis?

What sort of cultural factors and other barriers might make it more challenging for some families in Washington state to form social connections within the disability community in comparison to others?

How can the disability parent community and the healthcare system work more in unison to ensure that families are able to maneuver through the health system successfully from the start of their journey with a child with a disability?

Methods & Participants

Interviews

The primary methodology of this project was Zoom-based interviews. I conducted semi-structured interviews with four groups of participants: healthcare professionals, individual disability parents, care coordinators or patient navigators, as well as disability parent support group leaders or representatives of support organizations. It is critically important to note, as shown in Table 1 below, that ten participants were interviewed for this research, and multiple of them fit into multiple categories, which speaks to the fact that this industry is driven by people who are connected to disability in some way, whether they are disability parents, have a sibling with a disability, or have been a close ally for a large part of their lives. It is also of note that all of the participants interviewed identify as women, which speaks to the fact that the majority of caregiving and the majority of individuals in these care roles for people with disabilities are women, and it is often that women carry the large part of the burden in navigating care for their children (Heaman, 1995). The purple rows are participants who fit into just one participant category, blue rows are participants who fit into two participant categories, and the green are participants who fit into three different participant categories.

Table 1: Participant Categories

	Healthcare Provider	Care Cooridinator/Patient Navigator	Support Group Leader/Support Organization	Parent
Participant A	Developmental Pediatrician @ UW + SCH			
Participant B	Developmental Pediatrician @ UW + SCH			
Participant C	Child Psychologist @ UW Autism Center			
Participant D			Mandarin-Speaking Online Group via WeChat	🟦
Participant E			SCH/Odessa Brown Clinic Mindfulness Groups	🟦
Participant F		The Arc of King County	The Arc Parent to Parent Program	🟩
Participant G		The Arc of King County	The Arc Parent to Parent Program - Spanish	🟩
Participant H		Kindering		🟦
Participant I	Pediatric Physical Therapist	Private Consulting/E-Book		
Participant J		Children's Therapy Centers - Burien	Children's Therapy Centers - Burien	

Online (Facebook) Support Group Review

During the COVID-19 pandemic, the opportunity and availability for online connection in support groups expanded greatly, so it seemed very important to examine the unique support offered by online groups in addition to support organizations or in-person support groups. Facebook seemed to be the primary site used for parent groups. In consideration to protect these spaces and not interfere with them as a student researcher, I joined one, very large Facebook group with over five thousand members across the United States, that was specifically aimed for support and connection for caregivers of individuals with developmental disabilities. In joining the group, I stated my purpose for being there, being strictly observational and for research purposes that were to be entirely confidential, and collected both quantitative and qualitative data from posts only, not comments, for a two-week long period.

Participant Recruitment

I recruited participants for this research based on my personal connections at the University of Washington Medical Center at the Center on Human Development and Disability, at the UW Autism Center, and at Seattle Children's Hospital in the Neurodevelopment Clinic. From there, I used a "snowballing" method of recruitment, asking the individuals I interviewed who they suggested talking to for the purpose of this research. It was healthcare providers who suggested I add the category of patient navigators and care coordinators, and it was an individual parent who suggested I speak with support group leaders in order to gain a sense of these groups without jeopardizing the safety of their spaces.

Research Findings & Supporting Literature

Why do disability parents have such a difficult time navigating the healthcare system?

Social & Medical Models of Disability

The social model of disability aims to locate the problem with society, rather than the individual. The medical model of disability is where western medicine acts as the paternalistic expert of how to "deal with" disability, and locates the problems with the individual rather than with the social structures at play. As the social construction of disability has emerged and has been utilized by the disability community as a form of resistance to the medical model, there has been what is called a demedicalization of disability, meaning that attention has been shifted from a medical history of disability to a social civil rights movement (Kasnitz & Shuttleworth, 2001). It is explained that within the social construction of disability, there is a biological and a social component at play, and disability has become an identity marker rather than something that is negative (Wendell, 1996).

The social model does not aim to completely overthrow the medical model, as the disability community still sees the value and necessity of western medicine in improving their lives, but rather aims to share power with medicine to ensure that people with disabilities have a say over their own lives and are respected for who they are. For the purposes of this research, the goal is to understand how social supports for parents of children with disabilities can aid in learning how to navigate healthcare. Rather than an expert telling a parent exactly what to do, social supports are utilized by families to ensure that they have control over what is best for their child. This research operates through a social model of disability rather than a medical model, and aims to work as an example of shared power between western biomedicine and social supports for families who have children with developmental disabilities.

In short, the medical model of disability is the belief system of needing to "fix" those with disabilities to make them fit the typical mold of society. The medical model states that the lives of those with disabilities are challenging due to the fact that they are abnormal. The social model of disability argues that it is not those with disabilities that need to be fixed, but rather the social structures and institutions at play that need to change. An example of this is someone in a wheelchair, who is only given the option of stairs to get from one place to the next. They are confronted with an incredible challenge in this situation, not because their disability requires them to utilize a wheelchair, but due to the fact that there is not proper accessibility. This research serves as a means to integrate the social model of disability into medical practice and into the healthcare system, as it focuses on strengthening social support for these families and emphasizes the fact that we must change systematically rather than attempt to "fix" individuals with disabilities and their families.

Disability Discrimination & Stigma

The social model acts to resist the existing stigma and discrimination against those with disabilities. In the context of this research, it was imperative to speak about experiences of families who face stigma and discrimination the basis of having a child with a disability, and what this means for learning how to navigate healthcare and accessing parent social support after diagnosis. Parents' ideas of stigma and fear of discrimination can get in the way of not only their willingness to begin learning to navigate the system for their children, but also their willingness to seek out a diagnosis and accept that their child has a developmental disability. As a result of long-withstanding ableism in our society, many parents did not grow up around someone with a disability, have never interacted with individuals with disabilities, or are just unsure of the world of disability and what it is going to mean for their child.

When their child is diagnosed, there are a range of emotions that can occur for parents, and many of these feelings originate from fear of discrimination or stigma for their child and for their family. One of the patient navigators I spoke with mentioned that she thinks "stigma is something that gets in the way of people getting their diagnosis and getting on with things". Another echoed this by explaining that the biggest barrier for kids getting a diagnosis early and getting plugged-in to services early on is parents. "I feel like the biggest barrier is parents, in the sense that parents aren't part of the disability community, they haven't grown up with it, and so they are part of parent communities but not necessarily a part of the disability community, they aren't friends with people with disabilities themselves or getting into social justice issues with people with disabilities, things like that." The narrative that parents form when they initially receive a diagnosis can be filled with questions such as 'What did I do wrong?' or 'Why isn't my kid a normal kid?' Dispelling this narrative, as it is fueled by stigma and lack of understanding for the social model of disability, is something that healthcare providers, parent support group organizations, and disability parents who have been parents for a long time all aim to do, and it is far from easy. Kindness and gentleness are of critical importance in these conversations, and once stigma around having a child with a disability is overcome, parents are much more able to advocate for their children in navigating the health system.

Once parents begin to learn to navigate the system and overcome stigma around disability in their own minds, families can still face stigma and discrimination in other realms of their lives. In a conversation with a healthcare provider, she mentioned that one of her families received threats from their landlord, saying that they would be kicked out of their apartment if their child did not quiet down, despite knowing that the child is on the Autism spectrum and has loud, vocalization tics. Another large area of stigma is in interactions with "typical" families; one of the support group leaders I spoke with highlighted that a large topic of conversation lately is how to explain to other parents or their non-disabled children that their child has a disability. "When I'm at the park and my kid is out doing his atypical Autistic thing or wanting to play with another kid but doing it in an unusual way, what should I do? Should I go to the other mom and tell them? Should I go to the kid? Does my kid want me to share that he's Autistic? Does that help? Does that hurt?" Situations involving stigma and discrimination may have an impact on parents' ability to navigate the healthcare system for their children with disabilities. These experiences that families face can contribute to the ways in which they conceptualize how to go about providing care to their children.

It is also of note that a lot of the time, the medical model of disability is assumed to be the only model that healthcare providers subscribe to, meaning that healthcare providers aim to "fix" these children and operate out of stigma. In my opinion, yes, stigma and discrimination on the basis of disability do absolutely still exist within our healthcare system in some cases, and this desperately needs to change and should absolutely be condemned. Although, it also seems as if there has been a transition to most medical providers subscribing to the social model of disability. For example, every healthcare provider I interviewed for this research operates out of the social model of disability, still utilizing medical interventions, but rather to improve the lives of these children rather than "fix" them. This was also highlighted by a patient navigator I interviewed:

> "One thing that surprised me I think is that from my viewpoint in disability studies, you know we often hear about the medical model of disabilities and just viewing it as wholly part of the medical system so I thought that the medical system needed to change, that providers needed to change their viewpoints on disability. But I was surprised when I started practicing that providers were pretty open and were trying to help change the minds of parents, but parents, suddenly being thrust into this world, and not working in it every day like providers do, were a bit more out-of-sync I think with what I had been taught."

Overall, a transition from the medical model to the social model of disability both by parents, healthcare professionals, and society as a whole is what is necessary in order to reduce the stigma and discrimination currently experienced by individuals with disabiltieis and their families. Although for now, we must recognize that this community still experiences these harms in a very real way, and this research acts to work for this disadvantaged group.

Navigating the Healthcare System

Patient navigation can be defined as the process by which patients and their caregivers move through the multiple moving parts within a healthcare system to access and utilize the services provided in order to gain the most positive health outcomes and reduce the likelihood of inefficiency due to lack of coordination and fragmentation (Sofaer, 2009). Parents of children with special health care needs are expected to learn how to navigate through a bewildering array of healthcare services and systems that address their child's health, therapeutic, social service, and educational needs (Krauss et. al., 2001). It is rare for parents to feel supported and informed when they begin learning to navigate the healthcare system for their children. When parents first receive a diagnosis, providers are often unable to equip families with the resources they need to learn how to make their way through the hoops within the system. One parent interviewed explained that while the neuropsychology report she received was incredibly informative in terms of how to work with her child and support her child at home, "in terms of resources we could access, we weren't given anything at the point of diagnosis." One of the healthcare providers explained that "medical providers are expected, by the parents, to know these things, but they don't, and they don't have great resources for them to support their families." With limited time, knowledge, and expertise, it is difficult for providers to not only do their work, giving a diagnosis and explaining to a family what they need to do next, but also to work with them as they learn about waiting lists, what therapy centers are accessible under their insurance, and other sorts of nuanced struggles that families are going to face. Healthcare providers, in the nature of their roles, are unable to walk patients and their families through the hoops of the medical system, and so these families are left to fend for themselves. As much as they may wish they had the time to assist families in navigating care, they simply cannot.

There has been a push in recent decades of healthcare to improve our patient-centeredness, yet the reality of the structure and operating rules within our system is that navigating care is opaque and confusing for patients and families (Sofaer, 2009). Due to this lack of support from providers in terms of finding resources and accessing services as they learn to navigate care, most families end up struggling to understand what to do to best support their children. One of the doctors interviewed stated that the minority of her patients were “on it” or savvy when it came to navigating the medical system: “Maybe 25%.” A support group leader explained that “parents really want to do their best to support their loved ones, but it takes time, it takes years for them to understand the system”. Navigation of care takes place in a milieu of authoritative medical knowledge and knowledge from other sources, such as the internet, lived experience, and social connections (Willis et. al., 2016) Healthcare in the United States today is not patient-centered, but rather fragmented and complex (Sofaer, 2009).

Our healthcare system has often been described as a “nonsystem”, as it is much too fragmented, and the many moving parts within the nonsystem make it extremely difficult for even the most well-informed and generally healthy patient (Sofaer, 2009). Providers have often underestimated the complexity of the system that patients must navigate on their own, especially the majority of patients who are not a part of the “culture called health care”. Providers interviewed echoed their frustration at the complexity and fragmentation of our healthcare system. One doctor explained that "medical systems in general are difficult to navigate, especially the bigger they are, because there are so many different layers of people that you have to get through to get something done and sometimes the understanding of how to do something is not always standardized across all the different layers of people you have to go through.” One doctor even stated that she didn’t think, even with her educational and professional background in the healthcare system, that she would be able to navigate it on her own:

> “I'm always thinking, how would I handle this? As somebody who has practiced in the field of disability for 10 years, who knows how to navigate the medical system, who is generally an organized person, I don't think I could do it. And I'm English-speaking and I have connections within medicine, and I don't think I could do it. Some of it is the complexity and the friendliness of the medical system just don't jive well for anybody, like how could anyone ever do it, and then it's sort of like a match between the level of disability we're talking about and then the family and how savvy they are and how burnt out they are and what other factors they have that may be helping or hindering them."

Ultimately, the “nonsystem” of care that we have causes a lack of timeliness, effectiveness, efficiency, safety, and equitability in healthcare delivery for these patients and their families (Sofaer, 2009). And since problems in the navigation of healthcare occur more often for those who are less educated or sick, these problems contribute to greater inequity in healthcare delivery as well (Sofaer, 2009).

It is also rarely acknowledged that parents hold a role as “expert caregiver” and “care coordinator,” and both of these roles cause an additional burden on these families as they seek, receive, and adjust to a new diagnosis (Baumbusch et. al., 2019). Caregivers are expected to be “rational actors” who weigh available options and knowledge and utilize that information to make the best decisions about their child’s healthcare needs (Willis et. al., 2016). One parent explained that navigating the system is beyond complicated, and that doctors don’t fully understand what resources are available for parents, and asked “so, why the providers have a high expectation that families should know all of this language or ways of communicating as they navigate, I don’t know. So that’s why I believe that if we are on the same page, if the relationship and information between providers and parents is linear and not one-sided, it would be a lot better.” One healthcare provider explained that she recognized how our system fails to support families and recognized the dual burden they have as caregivers and as coordinators; "families have zero support, basically. They only have support if they happen to have a provider who can provide some support, but it's just kind of like, luck, if you have someone like that. So I don't feel like the system is providing any support." There has been a lack of research focused on the navigation of our complex healthcare system by parents (Baumbush et. al., 2019), and while it is assuring that the multiplicity of systems shows that we have a public and private dedication to supporting children with developmental differences, limited research has been done in terms of understanding the families’ experience in navigating and receiving these services (Krauss et. al., 2001).

A majority of the literature on this topic highlights the many challenges faced by caregivers in navigating healthcare services for their children with developmental differences. For example, Krauss et. al. ran a study on the contemporary experiences of families of children with special healthcare needs in order to understand the extent to which families are embedded in multiple systems of care. Issues reported by families included the difficult complexity of current health care service delivery, problems in obtaining specialty services, and hardship in coordinating services (Krauss et. al., 2001). The main problems indicated by surveyed parents in terms of accessing specialty healthcare services included getting referrals, appointments, as well as knowledgeable and skillful providers. It was also clear that parents ran into problems with coordinating services among multiple providers, getting the number of appointments needed authorized by insurance, and the extremely large expense borne by these families (Krauss et. al., 2001).

These problems faced by parents in navigating the healthcare system are incredibly frustrating and endlessly exhausting. One of the parent support group leaders that was interviewed commented on this:

> "In our last session, we talked about what's the real source of our trauma as parents, is it our kid or is it the systems we're forced to navigate? We really feel like in most cases it's the systems we're forced to navigate, like calling waiting on hold forever, making an appointment and they forget to call you back, or billing you for something you didn't do, and the insurance, and the… UGH it's just never-ending and that's just one system.

> That's not including Developmental Disabilities Administration, that's not including Social Security, and the schools. There are four, five, six MASSIVE systems you are forced as a parent to sort of master and navigate and dedicate time to, so that's a large part of what people talk about in our group."

One of the providers interviewed exemplified how nuanced care navigation can be for families, and how knowledge and resources in navigating care can truly set some families apart from others in terms of what they are able to do for their children. She explained that knowing certain "buzz words", knowing how to make certain phone calls, how to keep calling even if you have already called a million times, how to keep a schedule, how to stay persistent in getting on waitlists for therapy centers, or how to keep "pressing buttons" at certain organizations can end up getting you a quality medical team and therapy team. She said that in these instances, when families are resourced enough to know how to push these so-called "buttons", providers "might be having to sedate them less, they are not sick as often, and I would not be surprised if it led to fewer hospitalizations. So it can be pretty huge." Not only is there a benefit to children in terms of their learning and growth once their parents are able to navigate their care for them, but there is also a significant medical benefit for families who know how to maneuver through the system. There is also a financial benefit for these families as well once they learn how to successfully navigate; Baumbusch et. al. ran a study on parents of children with rare diseases, and found that following diagnosis, gaps and barriers to receiving services that could support their child's needs often resulted in out-of-pocket payments and changes to parental employment (Baumbusch et. al., 2019).

It is also important to mention how culture and belief systems play into the care navigation process for individual families. The way a caregiver views childhood disability provides structure and context for the development of a child with a developmental disability (Danseco, 1997). Parental beliefs are a means by which culture affects a child's development, and the caregiver's beliefs about the nature and causes of disability give rise to the context of choices regarding intervention and treatment for their children (Danseco, 1997). The link between caregivers' beliefs and intervention has implications for providing healthcare to families with children with disabilities, and this is particularly important for multicultural societies (Danseco, 1997).

Related Systems: Insurance, Developmental Disabilities Administration, and Social Security Income, among others

One provider mentioned that "as little control as we have within the medical system, it feels like we have even less outside the medical system." Related to navigating the healthcare systems, there are interrelated systems such as state systems and insurance systems in which these families must learn to maneuver through in order to navigate healthcare successfully. To begin with insurance companies, in short, one large issue was explained by one of the patient navigators interviewed, outlining that developmental medicine "is working really hard to get kids diagnosed at earlier ages and the Department of Health is cool with it, but the private insurance companies are not uniform in how they deal with it. And if 1 in 54 kids has Autism, let's talk about a huge wait list for therapies." Not only is the insurance world not keeping up with a greater recognition of developmental disabilities and the support that those with developmental disabilities require, but our Washington State government is also failing to keep up with supporting families who have children with developmental disabilities.

The Developmental Disabilities Administration (DDA) through the Washington State Department of Social and Health Services (DSHS) has been designed to support individuals with developmental disabilities throughout their lives, but one major critique of our Washington State DDA is that it fails to support families as they are trying to navigate the healthcare system when children are young. Washington State DDA prioritizes supporting people with disabilities as adults as opposed to when they are children, when compared to other states. One of the patient navigators interviewed explained that in some other states, children are enrolled in DDA or similar state programs while they are still in the hospital or when they are diagnosed by a social worker, and there is an emphasis on supporting children with disabilities, although oftentimes a lack of support for disabled adults. When speaking about Washington, she noted that "here, it's like families get almost no support throughout childhood, but then once children turn eighteen and become adults, they have a ton of support. But I think that's a big problem because families need these supports to help their children grow and achieve their true potential." If families qualify for the program, Washington DDA provides families with hours and financial support to hire in-home caregivers that provide respite and support for these families, among many other things.

Washington State DDA is a government program that is also very difficult for families with young children to qualify for, especially in terms of accessing in-home care. One of the patient navigators interviewed said: "I think some of the biggest issues [for families trying to navigate the system] are lack of support from the state. There is kind of this promise with this program of DDA, and most parents don't even get into DDA because they just give up on that process, so they don't even get hours or any financial support or anything. So I think that's one of the biggest barriers." The application process is long and tedious, and was explained by a parent as "a pain but really worth it if you are able to get caregivers. All of the assessments are based on deficiency and that's it, so most parents I know are just really down after they've had to do that." Enrolling in DDA and attempting to qualify for respite care is an extremely unorganized process; one of the providers interviewed stated that "I have asked so many families about this, about DDA, because once they exit Early Intervention Services, they should be applying for DDA, and they were just like 'yeah when he turned three, I was just kind of handed a bunch of papers and told 'you should do these things' and I never even got around to looking at the papers'. So there's no support from the systems even to help get people into DDA." Unfortunately, the Washington State systems that are set up to support individuals with developmental disabilities are often too complicated, too exhausting, and too difficult to qualify for, and it leaves families unsupported by the state. A doctor summarized this with an example:

> "DDA is a government system, so you're kind of just at the will of the government system basically and unfortunately, they don't make it easy to be qualified. It's a long process and there's a lot of hoops you have to jump through and there's a lot of things you have to remember and you have to schedule phone interviews and home interviews and it just takes a long time. And the same thing is true for Social Security Income (SSI); I have

> heard many stories of families qualifying for SSI based upon their income, and then either getting like a small raise or a change in the job and then all of a sudden they don't qualify anymore but they continue to receive payments from SSI, and then six months goes by or twelve months goes by and then SSI says ‘oops we were paying you when we shouldn't have and now you owe us $12,000.00’ or whatever. And it's like, that's terrible."

Overall, the state holds certain beliefs that are not particularly supportive to children with developmental disabilities. First, as previously mentioned, the state prioritizes supporting adults with developmental disabilities as opposed to children. Second, as summarized by a patient navigator, “I’m a big advocate of letting these parents be parents, and not be the organizer of their child’s life and care, and I don’t think the state believes the same thing AT ALL.” She also mentioned that:

> "There is a campaign out there for Washington that is something along the lines of 'parents save state money', like 'parents being the caregiver and doing all the navigating saves state money so the state should have some money for parents who can't do that', right? But it's not advocating for the norm that parents shouldn't have to do all that stuff for their child, they should be able to be a parent first. I think that perception from the state, at the state level, needs to change before we are going to have enough resources in DDA or enough caregivers or social workers to support these families."

In combating this stressful process of navigating the healthcare system overall and the other systems at play that determine a family’s ability to successfully navigate, there have been an array of proposed strategies on how to alleviate this burden on caregivers. Baumbusch identified that peer support, both online and in-person, was an effective resource for these parents, and was a key resource in terms of information and emotional support for these parents who often feel isolated and lonely at the beginning of their journey with a child with a rare disease (Baumbusch et. al., 2019). Willis et. al. propose that the most vital knowledge for navigating the healthcare system is “system knowledge”. System knowledge has two parts, the first being acquired knowledge, either through drawing on experience, formal information or undertaking research, which tends to be primarily cultural capital. The second part is assumed knowledge, which is used to access networks of privilege, which tend to be economic and social capital (Willis et. al., 2016) System knowledge can be explained in simpler terms as “the invisible rules of the game of healthcare” (Willis et. al., 2016) This research aims to explore the assumed knowledge piece of system knowledge, which can be gained through social networks of privilege, which in the context of this research, would be the disability parent community in Washington State. The disability parent community in Washington State is not only working to support these families in navigating the healthcare system, but also working to support families as they navigate state systems as well that affect their ability to do what is best for their children.

Aiding in Systems Navigation: Care Coordinators & Patient Navigators

There have been positions put in place in order to solve the expansive issue these families face in learning how to navigate the healthcare system. These individuals are often referred to as “care coordinators” or “patient navigators”. Care coordinators and patient navigators can be included at hospitals, can be included in support organizations, can be individuals within DDA or Medicaid, or could even reside within insurance companies. Patient navigators and care coordinators have the capacity to help families get on wait lists for therapy centers, assist families in learning how to seek out specific programs or clinics, can help families get doctors appointments or direct them to certain specialities based on referrals, and generally provide them with assistance with where to go, who to call, and what words to use in order to get things done. There is wide variation in what these individuals do, and for the purposes of this research, I only spoke with patient navigators or care coordinators in three different spheres: private care coordination and consulting, patient navigation at early intervention agencies or therapy centers, and navigation support at a parent support organization.

Healthcare providers are calling out for greater support in care coordination and patient navigation for their patients and the families they work with, as the time they have with families is limited, and their scope of practice does not include helping families navigate the system, as much as they may wish they could. Multiple providers spoken with echoed that they wished all of their patients had their own navigators, although one specifically noted that “but insurance won’t pay for that, so we can’t do that, and of course we can’t coordinate everything on behalf of our patients either because then we would spend all of our time doing that and nothing else.” Providers and parent support group leaders emphasized that care coordination and patient navigation seems to be a way that the state and the healthcare system have attempted to solve this issue. They spoke at length on the potential of these fields in helping families, especially in the initial period of diagnosis and learning how to navigate. One patient navigator interviewed said that “it is really important that everybody has the opportunity to have somebody to talk out with, okay what is this, what’s happening next, or if they don’t want to talk right now because they are still processing, then they know where they can go to hear a little more about what to do next.” The problem is that with the multiplicity of care coordination and patient navigation, the intention of helping families learn to navigate can become even more complicated when they don’t know which patient navigator or care coordinator to utilize. Many of the individuals interviewed, no matter their background, stressed the importance of fixing the problems with care coordination and patient navigation to ensure that they are more cohesive, more expansive, and more consistent for families. They also stressed that if there was a care coordination or patient navigation system in place that worked effectively to help these families, they would consider it incredibly worth the investment by the state and by the healthcare system.

In talking to patient navigators and care coordinators who do this work for families privately, through a support organization, or through a therapy center, it became very apparent that these individuals do a wide variety of work, and often have entirely different jobs from one another, despite all falling under the same occupational umbrella. One navigator, who is based out of a nonprofit organization, described her role, aside from running support groups, as “systems navigation all day long.” She explained her role as offering emotional support, and especially in the way of helping families find what they need. She expressed that sometimes, emotionally supporting someone means helping them find the means to what it is they need, and that this blurry line about her job is what she appreciates, because she can offer guidance in navigation but also emotional support as she speaks with families. She also added that her role is primarily phone consultation, meaning she lays out all of the options for families, meeting families where they are and trying to help them sort out all of the options they have to pick from.

A care coordinator I spoke with who started her own private business for care coordination described her role as more focused on community resources rather than medical resources, particularly dealing with day treatment centers, working through the process of establishing guardianship as these children become adults, and finding, or trying to find, in-home caregivers for families. One navigator who works at an early intervention agency and therapy center explained her role as helping families learn to advocate, understand what their rights are, and helping them understand how to navigate the system. She explained her focus on providing support post-diagnosis in terms of advocating for disability-positive language, advocating for neurodiversity after receiving an Autism diagnosis, and ensuring that families are educated and informed about the challenges but also rewards in raising a child with developmental differences. She also explained that navigators at her organization connect families with resources, with other therapies that they may want to seek, with parent support groups, and even websites, videos, books or podcasts that families might want to pursue after they receive a diagnosis. She also highlighted that much of the work that they do is getting families on wait lists at therapy centers and ensuring families are educated about what various therapies are intended for. At her organization, they also have separate individuals who serve as coordinators for DDA and insurance companies.

A different navigator, who works at another early intervention agency, spoke on her relationship with insurance companies, particularly in the work that she does for families. She explained that her role was established after a class action lawsuit against the insurance companies as a result of them denying Advanced Behavioral Analysis therapy to children diagnosed with Autism Spectrum Disorder, and money was set aside at early intervention agencies and other therapy centers which was meant to be devoted to someone who could help families with insurance, with understanding their options based on their insurance, and to help them understand how to move forward. As a mother of a child with a developmental disability, she explained that this role fulfills her personal missions and passions:

> "I am so happy to use my 'Mom PhD' everyday helping other families as they start on their journey. It has been such an honor to support families of all kinds of cultures and backgrounds. Getting to talk to parents that are just finding out about a diagnosis, I've been there, and I think I'm more empathetic than people that haven't been there, and I really do work hard at expressing how my journey has changed me and how I like myself way better than before Autism came into my life."

It seems that although care coordination and patient navigation are often muddled together, they may also have different purposes. It seems that navigators tend to focus more on connecting families to resources and helping to guide them as they get on wait lists and seek out therapies, whereas coordinators may focus more on insurance, DDA, and other systems in which families are also required to navigate as they influence availability of services. Either way, these two sets of individuals work for a common purpose, which is supporting families as they learn to maneuver successfully through the healthcare system for their children with developmental disabilities, and their roles are critical in ensuring families know what to do moving forward.

Limitations to Care Coordination & Patient Navigation

Despite the great potential and promise of care coordination and patient navigation, it seems that there are many issues with this system with its multiplicity, lack of cohesion, and overwhelming demand. To begin, these individuals are in extremely high demand. “We are so, super overloaded,” “Oh we're all over capacity, we are all definitely overstocked,” and “we are definitely always very, way too busy” were all echoed among the patient navigators and care coordinators interviewed. When asked if it was hard to access someone in her position, one patient navigator said “Yes. I have a caseload of over 90 kids. I am looking after over 90 kids at a time. And I have to keep track of where they are as far as seeing the doctor, I have to keep track of what ABA therapy is going to work for them, I have to keep track of them to make sure their diagnosis gets to the right person, and more. So no, there are not enough 'me’s'.” A different navigator who is based out of an early intervention agency and therapy center, when asked about navigation offered at parent support organizations, said that “I also think they are trying to do too much with too few people and so, I mean, that's just kind of the story of our lives." The demand for individuals to help with navigating the healthcare system is most definitely there, but the number of navigators and coordinators, and the limited abilities that they have, do not match the number of families seeking support or their full needs. In the words of the private care coordinator interviewed, she explained that there will always be demand for people to help navigate the system because “parents are still very burnt out and they still want someone to just do it for them.” Private care coordination is an option, but this is largely a resource available to privileged people only. One of the healthcare providers interviewed said that private care coordination “is a niche for resourced people. It’s kind of like people who can afford a life coach. Wealthy people can afford to pay someone to coach them through their lives, right, but poor people who don’t speak English are using the care coordinators through DDA or Medicaid, which I am in full support of, but there is just not enough of them out there to really make a difference.”

In addition to the fact that coordination and navigation are typically inaccessible to marginalized groups, another large issue with the care coordination and patient navigation systems is they aren’t coordinated systems at all; they are fragmented, they lack cohesion, and therefore they often fail to meet the needs of families in the ways they are intended to. All of the care coordinators and patient navigators interviewed mentioned that there is no formalized process, that care coordinators and patient navigators across organizations do not talk to one another to share resources and support they are giving to families, and that there is a lack of “divvying up” of duties. All coordinators and navigators are aiming to do too much, to do “everything” for these families, yet no one is getting it all done. And when a family has 4 different navigators or coordinators trying to do “everything” for them, it can lead to a lot of confusion, inefficiency, and greater stress for these families. One of the healthcare providers interviewed, when asked about care coordination and patient navigation, explained how, from the healthcare perspective, these two systems are set in place to help, yet often make things more confusing and complicated:

> "Care coordinators can be value-added and nonvalue-added and it's really dependent on the care coordinator, the person that's doing it, and how much support that person gets from their employer. Everybody says they have care coordination, every institution, but they don't have enough of them and they don't pay them well. And families can have care coordinators at their insurance companies, at the hospital, or at their therapy center. So there's not enough to provide the kind of support that families need, there's also too many of them for families to sort out which to go to for which purpose, and turnover can be really really high. The last thing you want is a care coordinator who is just starting and who doesn't know the resources yet, but you also don't want a care coordinator who is completely burnt out and who is disconnected and has lost their mission and their minds and hearts. There are not enough care coordinators; the panel of clients a care coordinator has far exceeds their ability to coordinate care for all of them."

Beyond the fragmentation of care coordination and patient navigation, the job itself is incredibly difficult, frustrating, and lacks proper compensation. One of the healthcare providers I interviewed said “sign me up, I could be a really great care coordinator, but I would hate it.” With the skills and knowledge of the healthcare system that she possesses, she has all of the power to help families through this process, but lacks the time as a doctor to do so. This work is painstaking as a result of the systems that our state has in place, and as a result, care coordinators and patient navigators often have lots of turnover, lots of burnout, and lots of difficulty staying with families for extended periods of time. The one private coordinator that was interviewed was actually in the process of stopping the work that she was doing, and deciding to keep her business to just her E-book and blog. After meeting the demand to help families get services and actually doing the work for them by applying to DDA or getting them caregivers, the consulting work became too frustrating for her to continue. She mentioned that she spent many hours and worked for months to try to find caregivers for families but would end up unsuccessful in finding them what they needed, which really took a toll on job satisfaction. She said: “there was some demand for what I was doing, I think because it was so frustrating, and because people struggled with it so much, but I couldn’t keep doing it because it was so frustrating.” As hard as she worked and as much as she knew about how the system worked, she was unable to get families what they needed as a result of the system, and ultimately it was too exhausting for her to continue and make it profitable. One of the navigators at a therapy center mentioned that staffing is incredibly difficult for them, and it is hard to hire people to do this work, despite always being very busy. Overall, the work of care coordinators and patient navigators is overloaded, fragmented, difficult, exhausting, and oftentimes lacking successful results, on top of the fact that it does not pay well enough. As a result, despite the promise of care coordination and patient navigation, families are left either with people in positions to help that cannot do what they need, or are left to fend for themselves. If people in paid positions are unable to do this work because it is too frustrating and exhausting, we can only imagine how gruesome this experience is for families, who are compensated nothing, on top of the other responsibilities they have to their children with developmental differences.

Parent-Provider Relationships & Medical System Trauma

It is truly alarming how prevalent medical system trauma and poor relationships with healthcare providers came up in this research. As a future healthcare provider, it felt incredibly important to include the stories of families affected by these interactions, and to advocate for change within the healthcare system. To start, providers, parents, support group leaders and patient navigators alike, discussed the extreme prevalence of medical system trauma. One support group leader and parent stated: “I mean every parent has a medical system trauma story. I really think that most parents also have people, medical professionals, that they would walk in front of a bus for, that they love and are so grateful for, so it's not all bad, but there's still a lot of trauma and a lot of really unpleasant and traumatic things that have been said and done." Another support group leader discussed this prevalence as well: “Something we talk about a lot in the meetings, more than anything else, is about when the professionals are not kind, first when they tell them the diagnosis but then where they can go, and we talk about how it is okay to not be okay." Many healthcare professionals continue to dominate the parent-professional relationship, assuming a role of “expert” acting in a paternalistic manner rather than cooperating with parents in the decision-making process. The needs and issues of parents are prescribed by professionals rather than expressed by the parents themselves, thus leading to disempowerment and marginalization of parents (Case, 2000). This in turn reduces opportunity for parental involvement in the care for children with developmental disabilities and hinders an equitable partnership to be formed between parents and providers (Case, 2000).

Another support group leader explained that with how often healthcare providers have told parents that their kids would never do “X”, and they end up doing just that when they grow up, she could start a website to prove just how harmful this language and lack of hope from providers can be. She said that “it would prove wrong all of the offensive and hurtful things that they’ve said that come up a lot.” It is proven that families are more involved in the accomplishment of goals set for their children with developmental disabilities if a strong parent-professional partnership is established. Although in the past and often present, this relationship has not been characterized as a mutual partnership, but rather a paternalistic system in which professionals lead decision-making when working with these families (Renty & Roeyer, 2006). This research aims to challenge the paternalistic nature of the healthcare system, and to aid in better parent-provider partnerships in Washington State in order to improve the health and well-being of children with developmental disabilities. It takes years for families to learn how to navigate the system, and with all of the emotions that go into having a child with a developmental disability in the background of this painstaking learning process, it is of critical importance that the healthcare providers that see these children are supportive, compassionate, and understanding as they serve them not only medically but also as they learn to navigate. A call for greater empathy and ensuring parent-provider partnerships rather than hierarchical relationships is critical as we move forward.

Ensuring Parent-Provider Partnerships in Healthcare Delivery

The healthcare community has come a long way in terms of ensuring partnerships with parents, and particularly parents of children with developmental differences. In speaking with providers that were interviewed, it became clear that each of them recognizes the imperfection of the healthcare system, the risks that their words can hold, and also the power of empathy and compassion when working with children and families. Regarding diagnoses, all providers that were interviewed echoed that making a diagnosis, in their minds, begins with parents' reports of their experiences with their child, their relationship with their child, and the things that the parents are seeing. Only then do providers' observations come into play to make a diagnosis or not. One provider said that "it is a collaborative dance that we do, both of our input is very valuable." Beyond diagnosis, providers talked about the importance of letting families take the lead in appointments to ensure that a child's true needs were talked about and met during the visit: "I have found that if I just engage with them on the thing they want to engage with, that creates the feeling of trust and mutual benefit and cooperation. Let go of your own agenda, basically, because I mean that's my agenda, not theirs."

It is of critical importance to prioritize listening in interactions with disability parents. Ensuring that parents know they are on a team with their doctors, rather than being subject to a dictatorship, was expressed in interviews to be incredibly important not only to reduce the chance of traumatic interactions, but to ensure that everyone is doing what is best for the child with a developmental disability. It seems as if healthcare providers recognize that because of the system, there is often only so much that they can do for a family. The thing they have control over is how they treat the family, the compassion they give in their interactions with patients, and their ability to advocate for the family's needs. One provider explained her approach and called for greater empathy in a way that perfectly sums up how healthcare providers can ensure parent-provider partnerships in their interactions with these families:

> "I feel emotional about this - I think the thing is that a lot of doctors just really don't take it personally, and it's like when you're talking to a family about their baby, it's really personal. I think I go into every interaction trying to treat this family like I would want to be treated. And if you were telling me that my child, who I had all these hopes and dreams pinned on, had a developmental disability, it would be devastating. And I work with brilliant people with disabilities all of the time but it is a harder life than we have as typically-developing people. And doctors need to not act like it's going to be devastating, not act like they know what it's going to be like, but just being open to all the different possibilities and holding the space and avoiding judgment. Treating the family like you would want to be treated, regardless of who they are, because what they are going through is hard."

Anecdote - Medical System Trauma & Ensuring Partnerships with Parents

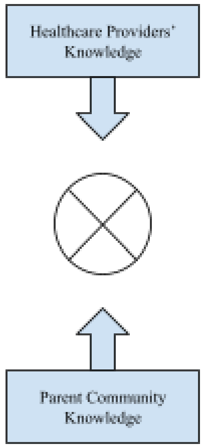
One of the disability parents interviewed, who also runs parent support groups, shared a story about a poor experience with a healthcare provider back when her child was getting diagnosed, and how she has shaped her career and her work in order to influence and reshape healthcare into a system that is more compassionate, understanding, and leveled with the parent community. She is an immigrant and English is her second language, and at the time that her son was going through a diagnosis, a pediatrician had essentially noted in her son's patient report that she was not taking proper care of him because she was protecting her younger child. Essentially, because her son had ADHD, he showed some aggressive behaviors toward his younger infant sibling, not in an intentional manner but just because he didn't understand that the baby wasn't a toy and could get hurt, and in the doctor's visit, the doctor seemed to think that because she was protecting the infant so much, that she was in a way neglectful of her son with ADHD.

> "The words that he put in the report made me feel like such a bad mom. This doctor made me feel like the worst mom in the world honestly. And remembering it, I get a recording or picture memory of the moment, and he was looking at me while I was looking at my son, and I was like 'why is he looking at me like that and my son like that' but at that time I was using an interpreter so I couldn't articulate all of these questions."

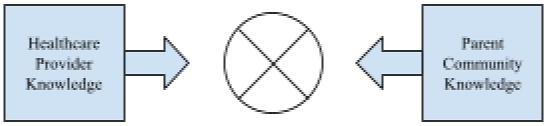
Since that time, she has transformed this experience into a career for herself running disability parent support groups for Spanish-speaking parents, and has played a part in teaching healthcare professionals about how to work alongside the disability parent community. She explained her most important message to healthcare professionals in regards to altering the ways in which they view their relationship to the disability parent community:

> "The professionals always do these kind of demonstrations where the information is here [gesturing at a level above her head] and the community knowledge is here [gesturing at a level below her face], so they want to make sure everybody comes together [hands meeting in the middle, with the community level raising and the professional level going down]. And I said no, that's not possible. If you really want to include the community, the providers are here [gesturing to the right side of her face], and the community is here [gesturing to the left side of her face]. It's linear. It's even. Nobody is up, nobody is down. To make this more inclusive and equal, everybody is on the same page. We may experience different situations but we need to be on the same page. I still respect the hard work that you guys are doing to go to school and it is very valuable for us, but it is very valuable for the families to be taken into consideration and to speak up and be able to advocate for their kids and be able to support their kids, because it is not easy."

Healthcare Professionals' Viewpoint:



Parent Community Viewpoint:



Problems Faced by Caregivers & the Need for Social Supports

Receiving a diagnosis of a developmental disability is almost always an unexpected, jarring event for families, and most caregivers are unprepared to cope with a diagnosis (Heaman, 1995). Countless areas of stress and hardship have been identified through research for families who have a child with a developmental disability. To start, the diagnostic period is usually a large area of stress for families. One of the parents interviewed explained that there is an emotional transition parents go through when receiving a diagnosis: "I think there is something emotionally that happens when suddenly something that was a delay, which sounds like it could go away or improve, is confirmed as a disability that is not going to go away." One of the healthcare providers who diagnoses children with developmental disabilities noted that "it's just so challenging and I'm so glad that personally I didn't have to go through that. I think I would know what to do but it just alters your life; it is such a life-altering experience, and no matter how positively you try and frame it, it is not what you envisioned you were going to be spending your life doing."

Beyond the emotional transition parents must go through after receiving a diagnosis, parents are then left to learn how to navigate a complex system for their children that oftentimes brings them even more stress than the diagnosis itself. Parent dissatisfaction with healthcare providers and delivery is most likely to occur if parental involvement in decision-making is lacking, if knowledge of available services is lacking, and if there is a lack of clarity within the diagnostic period (Renty & Roeyers, 2006). A study done with parents of children with Autism indicated that these parents experienced difficulty, specifically in the diagnostic process, in receiving support and education about their child's new diagnosis. These parents also reported difficulty in accessing Autism-specific services, but surprisingly reported satisfaction with the majority of these services themselves (Renty & Roeyers, 2006). In other words, on average, parents are pleased with the services that they are able to receive for their children, but trying to actually access such services is what causes them the most stress. As it pertains to this research, the period between initial diagnosis and getting "plugged in" with services is the focus, as this is reported to be the most indicative time period of parent dissatisfaction with gaining support and education about their child's diagnosis.

A different study conducted for parents of children with Autism reported that the most prevalent problems faced by these caregivers were: services are not effective in meeting the family's needs, providers do not communicate with or listen well to families, services are needed that were not currently available to them, delays and waitlists for accessing services, providers do not communicate with one another to work for the child, and available information on how to access services after receiving an initial diagnosis is extremely limited (Kohler, 1999). Overall, parents lack information about how to access services they need. This stress, confusion, and frustration in navigating the system, on top of the stress of having a child with a developmental disability, can lead to caregiver mental health challenges and caregiver burnout. The most prominent way in which disability parents have shown resistance to these challenges is by forming parent support communities as they learn not only how to navigate the health system for their children, but also advocate for them through the many challenges they face.

Caregiver Mental Health & Caregiver Burnout

In studying the disability parent community, it seemed incredibly important to discuss caregiver mental health and caregiver burnout as a result of the many underlying stressors that these parents face as they learn to navigate healthcare for their children. One study done on parents with children with disabilities revealed that 19% of parents met screening criteria for clinical depression; nearly one in five caregivers of children with disabilities experience depression as a result of navigating the complexity of their child's needs (Resch et. al., 2012). This prevalence was noted by healthcare providers interviewed; one said "I don't think there's any parents that aren't burnt out. I'm trying to think of any. I can't think of any. Even the parents who have caregivers to help." Another provider said that "pretty much all families are just maxed-out. They're burnt out." One of the parents interviewed who runs a support group said that she has heard from many individuals in the group that they are taking antidepressant medication to help their depression, and are open and honest about the struggles they face with mental health.

Disability parents have a dual burden of both parent and caregiver. Families who have children with developmental disabilities, as a result of lack of proper support, are at extremely high risk for burnout and mental health challenges, whether they have caregivers to come in and help or not. One coordinator mentioned that "even the parents who are self-employed, middle- to upper-class, who have caregivers so they can get away on weekends, still don't have enough support to just be parents." This goes to show that families who do not have the means to live flexible lifestyles or find support through caregivers are left with a significantly greater burden. One of the navigators interviewed spoke on her incredibly diverse and disadvantaged panel of families:

> "I would say 75 to 80 percent of the families are just trying to survive. They are on foodstamps, trying to pay rent. So understanding a system is way on the backburner because they are just trying to learn how to get their child to sleep or eat food. Evictions happen, families will report

> racism to me, get kicked out of their apartments, receive noise complaints, trying to find jobs, there is a lot. I would say yeah, 80 plus percent of my families are just trying to meet their basic needs and are already at burnout because they are home alone with multiple kids, some with disabilities, they're not sleeping well, they are not eating well, and they have really limited community to help them out."

No matter if parents are from advantaged or disadvantaged statuses based on a multitude of demographic factors, the common denominator is that these families have a lot more to worry about than just trying to navigate the healthcare system. So when we, as a system, do not provide them with proper support in learning to navigate, it becomes all the more impossible to accomplish when these families are trying to care and provide for their children with complex needs. No matter who they are, disability parents seem to always feel that they are not doing enough for their children. This was echoed by multiple providers and navigators, but one disability parent and support group leader summed this feeling up really clearly:

> "I think it's common, from the work that I do with parents and in parent support, that most parents seem to think they're not doing enough. That's pretty common. And then when you add in the disability factor and all of the extra things, suddenly your child talking or walking or eating actually depends on you engaging in therapies or learning how to find them appointments, and so there's this heightened sense that your child's development in a lot of ways depends solely on you."

It all comes down to the fact that parents of children with developmental disabilities are not challenged by their children themselves, but rather experience hardship as a result of lacking necessary social and environmental support as they provide for their children. These families want, more than anything, to do what is best for their children, but lacking proper support throughout the many challenges they face is the source of many mental health struggles and the burnout they are likely to face as caregivers. The idea of the "caregiver burden", being the perception that the caregiving situation they are in exceeds their capability and resources as a parent, can be better explained by a great lack of environmental supports rather than individual caregiver efforts (Resch et. al, 2010). A parent's well-being is affected not only by the specific child's behaviors or the situation's hardships, but largely by their interaction with social supports (Resch et. al., 2010). One of the support group leaders and navigators interviewed explained that the system is not ready for parents, no matter how hard parents try:

> "It takes a lot of emotion, you know, some families, when I provide a resource and they are not able to use it or get connected to it because of a waitlist or something, they come to me in tears and say 'I feel like such a bad mom' and I say 'Why?' and they say 'Because I cannot do this' and I say 'Yes you can, you are doing it, but because the providers don't respond or you are on the waiting list, despite you trying and calling, you WORKING, the system is not ready for you guys.'"

The lack of match between the needs of caregivers and the environmental support around them may lead to the perception of parents that their situation has exceeded their ability to succeed, which leads to caregiver burnout, burden, depression, physical health problems, and overall decreased quality of life (Resch et. al., 2010). The solution therefore lies within our ability to provide adequate social support to these families, to not only improve the lives and abilities of caregivers, but to ensure that children with developmental disabilities have the greatest chances of leading successful lives.

Caregiver Mental Health and Developmental Outcomes

In speaking to healthcare providers about the importance of addressing caregiver mental health, it became apparent that supporting disability parents who are struggling with their mental health is not only important based on prevalence, but also holds importance for the health, development, and well-being of their children with disabilities. To begin with what the healthcare providers interviewed had to say about the prevalence of caregiver mental health conversations, one provider said "I talk about the mental health of caregivers almost all the time." Another provider said that she talks about caregiver mental health approximately 75% of the time. When asked, "what triggers you or sparks you to ask a caregiver about their mental health?", one provider answered with: "them being in my office." Healthcare providers talk to caregivers about their mental health a lot, despite being providers that aim to serve children with developmental disabilities, and this, of course, comes from a sense of caring for the parents sitting in front of them, but also from a place of concern for the child's development and well-being.

When talking to providers about the associations between caregiver mental health and developmental or health outcomes of children with developmental disabilities, one provider noted that "caregiver mental health is extremely important for the developmental outcomes of these kids." Another echoed that "caregiver mental health is foundational for aiding in the developmental outcomes of children. They are 100% linearly connected." One provider talked about how many studies have been done on caregiver burnout, maternal depression, and other mental health struggles of parents that lead to worse outcomes for children, and she attributed this to the simple fact that if you can't take care of yourself, it is near impossible to take care of somebody else, much less somebody with complex behavioral, medical, or developmental needs. Another provider said that

> "a) the literature shows that caregiver burnout and mental health issues are highly prevalent in the community and in the nature of having a child with a developmental disability, and b) often, there are co-occurring genetic relationships with developmental delay or developmental disabilities and mental health disorders. So if the child is biologically related to the caregivers, then that's just something you need to be screening for. The big question that I ask almost every time is just 'How are YOU?'"

Not only do providers recognize the importance of addressing caregiver mental health, but support group leaders and disability parents echoed that they wished they had the opportunity in healthcare visits to speak about their mental health and be connected to resources, as they know it has a direct effect on the way they are able to support their children. Not only is caregiver mental health something that needs to be addressed for the sake of disability parents, but it has a direct impact on learning to navigate healthcare for their children, as well as a direct impact on children with developmental disabilities and their ability to reach their full potential.

Anecdote - Diagnosis Story and Caregiver Mental Health

One of the disability parents interviewed shared a story of when her children were diagnosed with disabilities in the Neonatal Intensive Care Unit. A nurse gave her the poem titled "Welcome to Holland" by Emily Perl Kingsley, which is a poem that essentially explains the situations disability parents find themselves in through a metaphor. The poem explains that you sign up to take a trip to Italy, just like everyone else, and you are super excited to go to Italy, and then when you get on the plane, they announce that your plane is actually going to Holland, and you must go there. You don't know anything about Holland, aren't prepared for Holland, don't really want to go to Holland, but it ends up being a beautiful place anyways. It isn't as exciting or as "flashy" as Italy, but Holland brings you joys you never would have received in Italy. Essentially, what the poem aims to portray is that being a disability parent is a very different journey than being a non-disability parent, and it may not be the trip you planned to take, but is beautiful in its own way. This parent explained the experience of receiving this poem in the NICU:

> "A nurse gave me the Holland poem, and I'm not sure if you're familiar with it, but I HATE IT. I hate it. I hate that poem. It was given to me way too soon. It was all this big metaphor about disability and it was given to me by a well-intentioned nurse in the NICU, but WAY too soon, because I had not gotten my head around disability yet, so that was a really upsetting experience. The reason I don't like that poem is because I think it's really glossing over the fact that there are a lot of challenges and a lot of grief and sadness with having a child with disabilities, and I think the poem maybe alludes to some of that in passing, but you know, I think yes, it's still an incredible and beautiful parenting journey, but I just feel like it makes this effort to make it sound like 'oh disability is just this beautiful place' and actually it's quite challenging. Yes, I agree, it's the most intense and beautiful joy you'll ever have in your life because when your child achieves things that other parents would just take for granted as a normal part of development, to you it's a really big deal because you didn't necessarily know if your child would walk or if your child would dance to music. But I hate that poem, and it was given to me way too soon in my grieving process."

Parent Support Groups for Caregiver Mental Health

The list of the hardships faced by parents is incredibly long. To alleviate the stress that these families experience, it is proven that the key is providing social supports. Support services for children with disabilities and their families can work as a buffer for the hardships of caring for a child with a disability, and being able to access such services results in better family adaptation and well-being (Renty & Roeyers, 2006). Informal support accessed by families caring for a child with a developmental disability are well-known, easily accessible, and effective; these informal supports including nuclear family support, spousal support, extended family support, and other sources such as friends, volunteers, religious groups, and support groups (Renty & Roeyers, 2006). In contrast, formal support, such as support from healthcare professionals and services, is often much less significant in reducing stress for families caring for children with developmental disabilities. The personal social network as a means of informal support is often much more crucial than formal support in stress reduction for these families and therefore in better health outcomes for these children (Renty & Roeyers, 2006). In other words, informal support has been proven much more effective in alleviating mental health challenges that these caregivers face, and support groups can be a means for these parents to find relief. One of the support group leaders interviewed discussed how caregiver mental health is talked about within her support group:

> "I think mental health and caregiver burnout is a lot of what we talk about and I almost think it's implied that we are all there because we are burnt out. I think that's why the group draws, I think everyone is there as part of their mental health self care. That's what I see the group as, it's self-care. When we talk about self care, we all roll our eyes about it like when are we supposed to do that? But I always say 'Well, you guys are here, it's 10:00 on a Thursday, and you've found some time to be here, and that's self care'."

Parents are able to receive informal support for their mental health and self care via support groups, and it is obvious that these social networks act as a means for alleviating the struggles these caregivers face. Therefore, I believe that it is of utmost importance that we begin to understand how we can improve formal support as healthcare providers to meet the needs of these families, and acknowledge the critical role of informal support via social networks (Renty & Roeyers, 2006). Not only do we need to understand how to improve formal support from the healthcare system, but we also need to have the healthcare system collaborate with informal support networks and utilize this informal support to help parents learn to navigate and feel supported.

The experiences of caregivers also differs greatly depending on many factors, one being between mothers and fathers. One study shows that the most predominant coping strategy for mothers was seeking social support, while for fathers the most predominant coping strategy was analyzing the problem and trying to understand it better (Heaman, 1995). One of the support group leaders interviewed said that she could not speak on the experiences of fathers because she primarily supports mothers. As much as they try to have fathers come to meetings, she has never had a father consistently attend her support group. It is important to note that the vast majority of caregivers interacting with the health system and taking on the large majority of the care are mothers, and understanding this need and tendency to rely on social support is critical to improving the way we support these families, particularly in terms of mental health and caregiver burnout.

How do disability parents rely on each other for support in navigating the healthcare system?

Community Reliance & Parent Support Groups

Despite the unique challenges of individual families raising a child with a developmental disability, one common stress that all of such families face is the continual struggle to live within a society that fails to understand and accept people with developmental disabilities (Ainbiner et. al., 1998). Parent communities and support groups serve as a means for promoting emotional support, a psychological sense of community, role models, means of accessing information, offering creative solutions to unique problems, providing an opportunity for parents to help others, a sense of control over their situations, as well as a source of friendship (Solomon et. al., 2001). One of the disability parents and support group leaders interviewed summarized the kinds of things that are talked about in her support group:

> "We talk about grief, grieving, we talk about behavior challenges, we talk about the way our homes look different than we thought they would because of our child's disability, like either they are messier or dirtier or there's less decorations up or there's a hammock swinging in the middle of the room, we talk about school challenges, independence skills such as what we think our kids might need to know, like how to do things before they leave if they are going to be able to move out. We talk about all of the things that we worry about."

Not only are these spaces meant for parents to share their worries and their struggles, but disability parent support groups and communities have also been proven to be helpful in both gaining a sense of control and agency in the outside world, as well as in self-growth and development at the individual parent level (Solomon et. al., 2001). Identity change is the most common theme as a result of being a part of parent support communities, and parents grow from victimhood to control, from receiving to giving to others, from confused to being able to negotiate with those providing help. Parental identity shifts from weak to strong, from depressed to confident and assertive, and from lost to finding a sense of belonging (Solomon et. al., 2001). Overall, disability parents rely on each other for support as they learn how to navigate the healthcare system and learn how to parent children with complex needs, but even more than that, rely on one another by building community in order to become empowered and to become the best advocates for their children.

Benefits of Parent Support Groups

To begin, disability parent support groups can offer a multitude of benefits for disability parents. The key is that parents find a group that fits with their wants and needs, and that makes sense for their family and their situation. One of the healthcare providers interviewed, in talking about her patients' parents who are involved in parent support groups, explained that the ones that are beneficial to families are the ones that

> "are capable of meeting the individual need of the family members or the caregiver, and those needs vary and are quite diverse; some families are seeking out actual, tangible support resources like caregivers or getting support for advocacy through the school or getting help communicating with insurance companies about therapy, and so some families are looking for that, and then some families are in groups and are just looking to connect with other parents about what things they're trying with their child that maybe their doctors aren't recommending that they find to be helpful. Or sometimes they're just seeking friendship."

Overall, parents seek out support groups for many different reasons, and the support groups that families find beneficial are the ones that meet that particular family's support desires. No matter why a family seeks out support, there are benefits to families in being included in support groups that have been made apparent throughout this research, and while some support groups only focus on maintaining their conversations on one of these benefits, other support groups may help one another in all of the following ways.

The first benefit of support groups is the exchange of information, both medically and regarding systems navigation. Parents involved in support communities and groups often find that there is a general "stock knowledge" available to them as part of group membership, and advice and information accessed via their support community is often the most valuable source of navigating the many challenging aspects of raising a child with a developmental disability (Solomon et. al., 2001). Families can connect with one another about medications their child is taking for ADHD, about what insurance companies are best for certain situations, about therapy centers in their area, about questions regarding a child's development, or asking questions about how to get medical equipment covered under their insurance. The exchange of information medically and in regards to systems is of incredible value to parents, and these conversations are where teaching occurs in terms of learning to navigate the health system from one another. Parents trust the advice and instruction of healthcare professionals, but often place higher value on the advice from those who have lived through the same situation and who they have formed trusted social networks with (Law et. al., 2002). Parents are the experts in doing what is best for their children with disabilities, and can do a great deal in providing creative solutions and emotional support in the face of hardships experienced by such families (Law et. al., 2002). Parents often discuss feeling as if they are in battles with the healthcare system and with healthcare providers, and often simply knowing that others are involved in similar battles can lead to greater strength and resiliency of individual parents (Solomon et. al., 2001). Multiple healthcare providers discussed the power of these support communities in connecting families with rare diagnoses; in our interconnected, technological world, families who have rare genetic conditions, for example, have been able to find one or two other families across the world who share the same condition, and can correspond with information about treatment breakthroughs. One provider explained that these families finally gain “a feeling of solidarity of like ‘oh this is somebody who actually gets it, who really knows what I am going through, or we compare notes and I realized that this treatment actually works much better for this particular child out of the seven families in the world that have this condition or whatever.” Beyond rare diagnoses, parents of kids with generalized developmental disabilities can also gain support, advice, and knowledge regarding their child’s health and navigating their child’s care from other disability parents in support groups. One of the support group leaders interviewed mentioned that when one person in her group learns something new from their healthcare professional about the way their child’s brain works, or a resource available for learning how to apply for DDA, or a way that social work can help with certain things regarding insurance, they pass it along in the group. She said “it's always responses like: ‘okay I will use that’ or ‘oh someone told me about this so I’m going to try it and bring it up to my child’s doctor’. So I think this is something that the families really benefit from.” It has been proven that having increased social support translates to better access and knowledge in navigating resources and healthcare decisions for these families (Singh et. al., 1997). Being a part of a disability parent community leads to a greater sense of self-efficacy in healthcare navigation and decision making for families raising children with developmental disabilities (Law et. al., 2002).

Another benefit of parent support groups is a feeling of solidarity, of community, of connection, and of commonality. Parents embedded in support groups echo the importance of not feeling alone in their struggles, and often the most rewarding part of being in a support group is that parents form lifelong connections with fellow disability parents. Some groups end up hosting parties, playdates for their children, join sports teams, and connect with one another in “normal” aspects of life as they all understand one another. In our world today, especially exacerbated by the COVID-19 pandemic, it can be hard for anyone to build community, yet alone families who have children with complex needs. One disability parent explained that back when her child was diagnosed over 20 years ago, all of the therapies they attended were in-person and at the therapy center, and all of the mothers would have to wait out in the hallway, and naturally built community that way. Now that many therapies are offered in-home, especially as a result of COVID-19, families find themselves not only isolated as a result of having a child with developmental differences, but also isolated from building community with people who understand what they are going through. It is hard for families to naturally find and connect with people who “get it”. Disability parents experience feelings of grief, loss and guilt in addition to social marginalization, stigmatization and disempowerment, and support groups and communities serve as a way to band together in these experiences (Solomon et. al., 2001). Professional agencies such as the healthcare system are of limited nature and simply cannot address this social isolation experienced by disability parents, and therefore support groups and communities are often most helpful for these families. Social support acts as a buffer against the continual stress and isolation experienced by these families (Ainbiner et. al.1998). Parents involved in support groups feel that they can share both the positive, such as hopes and accomplishments of their children, as well as the negative, such as fears, struggles, and disappointments they run into in raising a child with a developmental disability (Ainbiner et. al., 1998). Having a community of people who can share in common challenges but also common triumphs is a very significant benefit to support groups, and this was echoed by every single person interviewed. Overall, parents gain increased skills, sense of power, sense of belonging, and means of connection as a result of support groups. This in turn leads to a resiliency, both on the individual and community level, that combats the struggles and issues in the day-to-day experience of raising a child with a developmental disability (Law et. al., 2002). One parent and support group leader shared that in her support group, “I can feel that I am not alone and that I have many similar friends with similar situations and we can support each other. So that gives me very strong support to meet the daily challenge.” Another parent and support group leader shared what she believes to be the biggest benefit of support groups:

> “The benefit is that you’re not alone. You’re not doing it alone. That was the biggest relief to me when I met other parents, I was like ‘okay.’ Social media can have you thinking that everyone's family is great, everyone knows what they're doing, they're all having these lovely moments and ‘if only they knew my house is like pandemonium and misery all the time’. And then you meet other disability parents, and some people will say 'well I went to a group and I thought I had it bad and then I heard what they had and I realized I don't really have it that bad'; I don't really love that, I don't want to take pleasure off of other people's difficulties, but I try to frame it as I am inspired by what they are experiencing.”

This feeling of community, of solidarity, is what parents find to be critically helpful as they juggle the many difficulties they experience. One study done on Parent to Parent support found that disability parent support groups work as a means to create “reliable allies” (Ainbiner et. al., 1998). A “reliable ally” forms a relationship based on perceived sameness, situational comparisons that foster learning, constant availability of support, and mutual support (Ainbiner et. al., 1998). Parents who are able to find themselves in a relationship with a reliable ally and fellow parent are better able to receive support when needed, find growth in their commonalities, and foster an ongoing connection that improves their ability to navigate the health system along with the daily life of raising a child with a developmental disability.

Another benefit to parent support groups is the exchange of resources, such as ways to find caregivers, disability parent support organizations, or even websites, books, videos, and others that can help disability parents educate themselves and make the best decisions for their families. One parent mentioned that they discuss, a lot of the time, different websites you can post caregiving jobs on in order to find caregivers. Another example could be that a parent watched a documentary about the disability community and about disability-positive spaces, and encouraged families to watch it. Some parents also share more avenues for parent support, such as mentioning that they are part of other support groups, or sharing that they talk to a specific organization’s patient navigator when they have questions about navigating the health system. Experienced disability parents remember what it was like to be in the “newly-diagnosed shoes” and offer tremendous support and advice when it is asked for. One parent noted that “if newly diagnosed parents have questions about maybe where to get a resource or how to solve some daily routine problem for their child, it’s quite easy because there are a lot of experienced parents in that group willing to share.” In these groups, resources are disseminated widely, and often this information is valuable, trustworthy information in which families can utilize to their benefit as they learn how to raise their children or navigate the healthcare system.

In parent support groups, advice, tips and tricks, and stories are shared in order to connect with one another but also to support parents as they face difficult situations both with their children and with the healthcare system. Particularly, this advice is given by parents who are more experienced or who have resources or information to share with parents who may not know what to do. The key is that this advice is asked for rather than unsolicited, which will be discussed later on. One support group leader mentioned how this advice sharing can be useful for newly-diagnosed parents but also useful and supportive for the "advice-givers" as well:

> "My group is the catch-all for anyone. There's parents of kindergarteners and there's parents of kids in their 30's there, and as a facilitator that can be really stressful because one of my goals as a facilitator is to take whatever someone is talking about and be able to generalize it so that other people can support and empathize with it or share their experiences about it and that can be really hard to do when you're talking about a 5 year old and a 30 year old. But this group, the younger parents really appreciate the wisdom and expertise and experience of the older parents, like they don't resent it, and the older parents love to encourage and I think that when their advice is seen as wisdom, it feels really good and that is supportive to them."

Disability parents, in addition to the many benefits of support groups, gain a sense of satisfaction from sharing their experience and knowledge with other parents in need. Not only do support groups serve as a means for receiving advice and information, but even more importantly, they act as a means of mutual support, allowing the experience of parents to be dynamic over time, switching from receiving to giving useful information depending on the circumstance (Solomon et. al., 2001). This mutual support is invaluable to parents; it combats disempowerment and builds long-lasting community and solidarity in the face of the hardships experienced by families with children with developmental disabilities. Mutual support serves as a way of building individual and community resiliency, and in turn leads to better outcomes not only for disability parents, but for their children with developmental disabilities as well.

Another significant benefit of parent support groups is that, because of the fact that individuals with disabilities are still discriminated against and stigmatized in our society, disability parents can become empowered advocates for their children. Disability parent communities have served as a means for empowerment of these families; empowering parents leads to positive change in these families' lives, and helps parents make changes to better advocate and support their children with developmental disabilities (Singh et. al., 1997). Parents become empowered and learn to advocate for their children in many different ways; they learn how to advocate for their children in school, in insurance coverage, in healthcare decision-making, and many other instances in which they may be treated unfairly or disproportionately. Family empowerment is a means of increasing parental access to knowledge, support and skills that enable them to exert greater control over their lives and the lives of their children (Singh et. al., 1997). The empowerment status of a family is often a critical factor in understanding their ability to succeed or fail in accessing services and utilizing such services in the best way possible (Singh et. al., 1997). Lacking empowerment leads to families feeling overwhelmed and powerless in attempting to navigate the healthcare system for their children (Singh et. al., 1997). In one study on such parent support groups, membership within a support group or parent community was the factor that most influenced a family's level of empowerment. Results proved that membership within such a community was most strongly associated with a family's ability to advocate for their children and act in an empowered manner as they navigated the service delivery system (Singh et. al., 1997). Overall, parent support groups can be places where empowerment and disability activism are cultivated, and these spaces act as a means for parents to gain strength in their ability to ensure that their children lead accessible, equitable lives.

There are many more benefits to parent support groups, but the last major benefit that was apparent throughout this research was that these spaces give rise to the opportunity for diverse people, or niched people, to connect with one another. For example, one of the healthcare providers interviewed explained her observation that with the rise of online meeting spaces such as Zoom, "smaller groups or pockets of people who experience life very differently than white, cis, hetero American culture, can connect virtually if they have the resources to do so." Groups are formed based on ethnicity, language, sexuality, and many other demographics that intersect with the disability parent community, and the opportunity for these individuals to connect with one another holds great importance, particularly for those families who face multi-layered discrimination based on other demogrpahic factors underlying disability. These spaces provide opportunities for individuals to connect and to rise up against the unique challenges they face as part of a particular group, and this benefit to parent support groups is incredibly important to keep in mind moving forward as we learn to better support families of diverse, and often disadvantaged backgrounds.

Concerns with Parent Support Groups

With as much promise as disability parent support groups hold, unfortunately, there are also some major concerns. Just as the healthcare system has its faults and gaps, so does the disability parent community, and the system of support groups that currently exists in Washington State. An overarching problem with parent support groups is that they are either dwindling, can't seem to get people to regularly participate, or struggle to stay alive. While they provide excellent support for those who commit to them and engage with them, it seems that support groups are struggling to maintain traction. One patient navigator said that "I do not know what the answer is to support. I just know that as a whole, every organization whose deal is to gather is in upheaval right now." Among the benefits of parent support groups, as mentioned before, finding a group that is the "right fit" is of critical importance, and oftentimes this process is extremely difficult for families. There are many concerns raised with support groups that make it difficult for families to find a proper match for their needs.

The first concern, which may be seemingly obvious, is that some parents aren't "support group people", meaning that their personalities or desires simply do not align with the nature of support groups. Some families do not desire support from others, and therefore these groups do not draw a lot of attention from people who may like to keep more to themselves, for example. One of the healthcare providers interviewed explained that while some families may be interested in medical advice or suggestions from other parents, others may not trust others or may feel judged for approaching their child's care in a particular way, and therefore these groups are not a good fit for them. Some people may find recommendations exciting and valuable, while others may feel overwhelmed by more information or fear that people will disagree with their approach. In speaking with this provider about if she recommends support groups to parents or not, she explained that she first asks families if they are interested or not, because some people, as previously mentioned, just aren't "support group people". She explained that "some people have their own built-in support network which is their extended family, close friends; some don't feel that they are really helped in support groups. I am always sure to ask, before throwing them out there, 'Do you want to meet with other people?' 'Do you want to get support or information from others?' 'Do you want other resources instead?'." What it comes down to is what a family's needs are, and if their needs do not require or do not match what a support group can offer, then they won't seek out a support group. In turn, support groups sometimes struggle to draw people for this particular reason.

A major concern about support groups are language and cultural barriers to support. These two barriers to accessing support were stressed time and time again throughout this research, as these barriers often make accessing parent support impossible. One support group leader, who identifies as a white woman, explained that as she has tried to run support groups for multicultural families with many different ethnic and language backgrounds, there has been a conflict within her:

> "The cons [to support groups] for sure are the language barriers and cultural barriers. You know, it doesn't feel great if you're a white person saying 'hey, let's talk to families of color and pretend we know how they feel'. So not really having enough variety in our staff to represent families can feel icky. And then we use interpreter services at our center, but support groups are harder because we have to do an interpreter channel via Zoom which is really complicated, so it's near impossible and another barrier of figuring things out. It takes extra time to do it and a lot of the time we just don't have that time in our day on top of all of our other responsibilities. So I would say just not having the right representation, and families maybe feeling uncomfortable about coming to a group, not seeing any people that are like them, and yeah language just always becomes such a significant barrier."

Another support group leader mentioned that in her group, she hardly gets any non-English speaking families to come because it feels like such a barrier to them, even in understanding what is being talked about and feeling comfortable sharing about themselves through an interpreter. She ended with: "it is far from equitable for them". The barriers to accessing parent support groups are still major downsides to the efficacy of these groups in helping all backgrounds of disability parents navigate the healthcare system. More will be discussed on these barriers later in terms of accessing parent support, but what is of critical note is that these barriers prevent disadvantaged groups from accessing these spaces and benefitting from them, which contributes greatly to inequity in navigating healthcare for children with developmental disabilities.

Another large concern posed by those that were interviewed can be generally summarized as a fear of not "fitting in". One of the support group leaders interviewed explained this phenomenon, and how common it is for parents to be hesitant exploring parent support groups as a result of this fear:

> "I felt this too when I was in their shoes, but parents always think they aren't going to fit. They think 'oh their kid is way more disabled than mine' or 'my kid is way more impacted than all of theirs' or 'I'm a single mom so they won't get it' or 'I'm gay I don't belong' or 'I'm too poor' or 'I'm not educated enough' or 'I'm too educated and too wealthy to complain about my life'. I am telling you, every single person has a reason as to why they think they won't fit. For me, it was that my kid didn't have a diagnosis yet, so I didn't think I'd fit into that group because they all had diagnoses already. So that's been interesting to me over the years is to hear everybody's reasons as to why they won't fit in a support group."

One of the reasons why people believe they don't "fit" that turns them away from parent support groups is that some families have unique challenges, such as dual diagnoses, meaning two different diagnoses. This was brought up by multiple research participants. Essentially, it was explained to me by one of the healthcare providers that some families with dual diagnoses, for example, their child has Down Syndrome and Autism Spectrum Disorder, struggle to feel that they belong in either Down Syndrome support groups or Autism support groups, as the two diagnoses make their child particularly unique. Their child is not similar enough to the kids of the parents in the Autism group, but the same holds true for the Down Syndrome parents group. She said that "they actually tell me that being with the regular Down Syndrome support groups has not been helpful because their child is so much different than the other kids, and so then they kind of feel more of an outcast and more sad than they did before joining." Another provider explained this same phenomenon:

> "A lot of kids don't fit into a specific bucket, and I think we're finding that more and more, support groups are compartmentalized to Cerebral Palsy groups and Autism groups and Down Syndrome groups, but so many kids have rare genetic disorders that, you know, twenty years ago they probably would have just put them into the Cerebral Palsy 'bucket' but they don't fit in that anymore. Now a lot of families don't really have a lot of resources to reach out to, despite how many groups there are, which is really unfortunate."

What is most concerning about this aspect of disability parent support groups is that they are intended for parents seeking out support and connection, but oftentimes, these spaces either do not properly accommodate all individuals, or parents hold fears that they will not be able to relate to other families based on their unique situations. When a desire for support is matched with an inability to fully connect with your niched group based on a demographic or your unique needs, you are left feeling even more isolated and lonely than before you reached out for support, which is incredibly concerning. This is one, massively daunting challenge that disability support organizations are attempting to solve, but for the time being, acts as an incredible hindrance to accommodating all disability parents.

Another concern and reason that disability parent support groups struggle to gain consistent participation is that people often say that they don't want to show up and listen to more "sad people". Disability parents, as previously detailed in length, experience a multitude of hardships, and often parents are deterred from support groups because they feel as though support groups are all about talking about those same difficult things. One of the support group leaders said that she hears this reason for not joining her group the most: “they say, ‘I don’t want to listen to sad people, like I’m sad already, I can’t handle other people sad.’ So that’s the biggest drawback I hear. I think the problem with this is that not all groups are well-facilitated, and these spaces can get stuck in sad spaces only, which really deters people.” The thing is, multiple support group leaders talked about how they avoid getting “stuck in sad spaces only”, and one particular support group leader explained that the sad things are “not what goes on at our group. We do occasionally cry, that happens, we also laugh I think a lot more than we cry, a LOT more, and I think it’s never everyone crying but just one person who, when they share what’s going on in their lives, might get a little bit teary and we allow for that, we respect that, there’s a lot of empathy and compassion, but then we move past it.” Overall, one concern about parent support groups is that heavy conversations are definitely had, but there is a fear that the conversations will only be heavy, and without proper facilitation to keep these spaces both respectful of hardship but also positive and uplifting, they can become stressful for families rather than supportive.

On the same lines of support group facilitation, lack of proper facilitation in terms of advice-giving is also a concern of disability parent support groups. Some groups struggle to stay focused on a topic and become derailed, sometimes one person dominates the entire conversation or meeting, the conversation can turn to making the space unsafe for everyone where accusations are made or there is unsolicited advice-giving, and as a result of this improper facilitation, things can go wrong very quickly. Supportive spaces can become unsupportive without proper guidance by a group facilitator. One support group leader spoke at length on how important it is in a support group to talk about how certain situations shared by other parents can be generalized and applied to everyone’s life. She talked about how, as a group, the point is to connect with one another when talking about experiences, and so she focuses on ensuring that when someone tells a story or shares a problem they are going through, that she has time afterwards as the facilitator to generalize the learning to the whole group. She also mentioned the importance of ensuring that advice is only given when asked for. Her organization lays ground rules that she is proud of, because she once had an experience that was unpleasant in a support group when her child was first diagnosed: “we are really good about setting up the rules of ‘don’t give advice, you’re not here to give advice unless people ask for it’ and that is really important. That’s where my own experience in a parent support group was hard because another woman was commenting on my experience and saying ‘oh that is no big deal’ while I was still grieving and overwhelmed.” She stopped attending this group because it was not a supportive space for her at the time, and as a result of lacking proper facilitation, she was harmed as she was trying to seek out support in the parent community.

Another concern about support groups is that some require a time commitment, and disability parents often have hardly any time to take a shower or catch up on sleep, let alone attend a support group meeting. Some support groups are curriculum-based, where they require that parents attend for a certain number of weeks and each week is a different topic, and one of the support group leaders explained how difficult these can be for disability parents because “our kids are unpredictable and they are our biggest priority and we have other kids, and spouses, and dogs, and all of the other things to deal with that come up.” Some parents have to be so focused on the needs of their children, so much so that even the thought of taking time to get to a support group takes up too much time. One of the navigators interviewed used to run support groups at her organization, and explained that because of how busy these parents were with their children, "it got to the point where nobody would come. We would get everything ready, and nobody would come, because they just didn't have the capacity."

The last major concern that arose during interviews, although there are many others, was parents' hesitation as a result of fear of judgment in these spaces. Some parents fear that they will be judged for the medical decisions they make for their children, their parenting decisions, or even factors outside of their control such as demographic factors. One of the support group leaders talked about how she tries to eliminate judgment in these spaces:

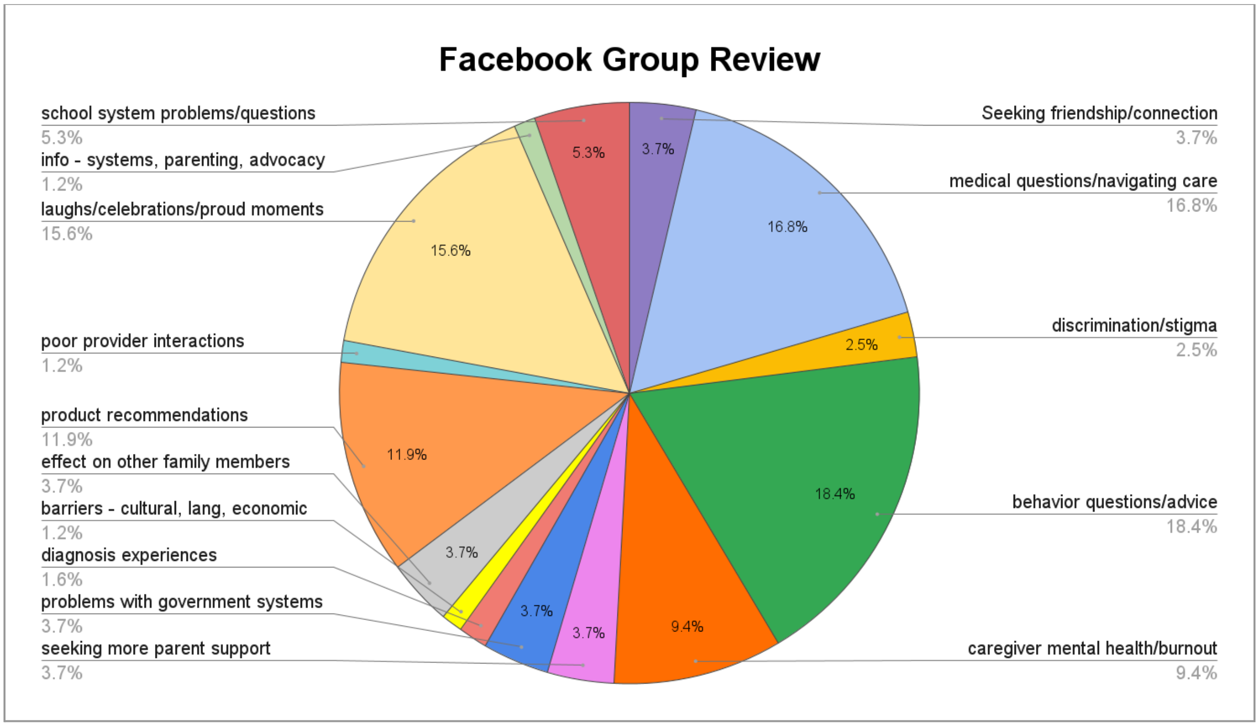
> "I have really taken the approach of 'this is a really laid back thing, just pop in when you can and pop out when you have to leave, we are just glad to see you no matter what you are able to do'. When we first went to Zoom [during the COVID-19 pandemic] I really made a big effort in my promotions for the group to say 'I don't care if your house is a mess, I don't care if your kids are climbing all over you, if your dogs are barking and your hair is dirty, I don't care about any of that'. Even now that we are used to people seeing our houses, there are still kids being crazy or the husband is running through in his underwear or whatever, we are all very 'yah that's how life is' and there is a very big effort to be a non-judgy space, and as a facilitator I have made that very clear. I like to tell people that 'there's nothing in your house that hasn't happened in mine already.'"

Overall, no matter the reason that parents may fear judgment in support group spaces, this is a factor that hinders people from joining support groups, but also if they feel judged or begin to fear judgment in the spaces that they are a part of, it becomes impossible to feel supported. There are many concerns about parent support groups, despite the many benefits to being a part of these communities, and what it comes down to is the individual parent, their needs, and how they feel supported or not supported by these parent networks.

Facebook Parent Support Group Review

Disability parent communities and support groups are also becoming more and more accessible as the rise of social media continues to influence the ways in which we are able to communicate with others, especially since the COVID-19 pandemic. Social media has served as a means of communication and support in recent years, and has shown numerous benefits including increased accessibility, access to health care information, and increased interaction with others for families raising children with developmental disabilities (Russell et. al., 2016). Social media has also become a new means of connecting and improving health communication. The benefits of social media for health communication can include greater accessibility and sharing of health information, peer and emotional support in healthcare decision-making, public health surveillance, and the potential for influence of health policy (Russell et. al., 2016). As a result, many parent support communities have found themselves occupying online spaces and capable of accommodating people of many different backgrounds. For the purposes of this research, it seemed critical to examine the potential of these spaces in order to compare them to other forms of parent support. To make it clear, online groups in this research are being defined as spaces that do not meet "live". In-person groups, as previously discussed, are groups that either meet face-to-face, or as a result of COVID-19, meet "live" via Zoom or another platform. For the purposes of online groups, these are spaces that only reside online, and do not meet synchronously.

For the Facebook Group Review, a private Autism parents group with over 5,100 members was chosen, and as previously mentioned, I observed the posts that parents made for a two-week-long period in March of 2022. Over the course of 14 days, I observed the posts that Autism parents shared with one another, categorizing them and recording generalized examples in my notes of what posts said that particularly stood out. Within those 14 days, 146 posts were shared, and as I categorized them, many of them fit into multiple categories, so sometimes posts were counted in 2-3 separate categories. Below is an in-depth summarization of the data I collected, along with some examples of the posts in each category.



To begin with the figure above, the four categories that had the most posts shared were behavior questions/advice, medical questions/navigating care, laughs/celebrations/proud moments, and product recommendations.

To start with behavior questions/advice, which made up 18.4% of posts, these were usually questions regarding their child's behaviors, as Autism Spectrum Disorder can present with many behavioral challenges in children, and parents posted stories and asked for advice about how to deal with certain behaviors. Some examples of these were questions about vocal stimulations, what to do when your kid unbuckles themselves in the car every time you get on the freeway, how to transition your child to sleeping in their own bed, or how to work with your kid to stop harming themselves or consuming unhealthy substances. Logically, it makes sense that the majority of the conversations in this group revolved around behaviors, as these parents all manage their child's unique Autistic behaviors, and can all offer advice when it is asked for in a post. Behaviors are also a large source of stress and a part of daily life for these families, so seeking out support in this space was a way for parents to brainstorm new things to try, new ways to approach their parenting, or have the opportunity to vent about how frustrated they are, and have people to listen that have a mutual understanding.

The second most common category of posts were medical questions/navigating care, which made up 16.8% of the posts. This means that 1 out of every 8 posts, on average, was related to learning how to navigate healthcare and navigate the medical needs of their children with developmental disabilities. A lot of these posts were about engaging in various therapies; wondering if they should cut back on certain therapies or not, wondering if insurance will cover certain types of therapy, inquiring about the risks and benefits of therapy, and seeking out more information about therapies in general. Some posts were about healthcare providers; whether or not to trust healthcare providers, what to expect before seeing a certain kind of specialist, or trying to understand unclear information given by providers. There were questions about medications; wondering about side effects of taking specific medications, discussing dosages of medications, or asking for recommendations of medications that might help their situation. Some questions revolved around how diagnoses are made, if it is possible that their kid might have another diagnosis besides Autism, asking where to seek out evaluations for new diagnoses, asking what parents think in regards to a dual diagnosis for their particular child, and even seeking diagnoses for themselves after their children have gone through the process. There were questions about medical or healthcare visits, many of which talked about how to help children with sensory challenges tolerate masks during COVID-19, and helping children cope at other appointments such as dental visits. Last, there were many questions about insurance coverage for particular healthcare situations, such as "Who do I send this email to?" "Who tells me if I am going to have to pay for this service or not?" "How do I advocate for us to get more services covered by our insurance?" or "My doctor told me to call this person but I am not sure what to say to them to get the correct message across." Overall, the posts related to medical questions/navigating care showed very clearly that these parents relied on one another, and on their online space, to learn how to navigate healthcare for their children.

The third most common category was laughs/celebrations/proud moments at 15.6% of posts. These posts primarily included pictures and videos of their children, and either involved something funny that their child did or a funny story about their child, or talked about how excited they were that their child learned to do something new. Some of the other posts were pictures of children enjoying things like water parks, experiencing new things with big, happy smiles on their faces. Parents shared funny stories about their children asking them uncomfortable but comical questions, or posted videos of their child waving goodbye to his therapist for the first time. One parent even dedicated a post to inviting people to share funny or lighthearted stories about their children in order to cheer everyone up and see the "bright and beautiful side of Autism". It was particularly exciting to see that these posts were as prevalent as they were; these parents rely on each other for lighthearted connection and community as they face difficulty as disability parents, and share a common joy in the unique victories of raising a child with a developmental disability.

The fourth most common category of posts was product recommendations. This was definitely unexpected in this research; the amount of consumption and consumerism in regards to children with Autism was something I was unaware of before observing in this group. Most of the time, these posts included a picture, video or link to a product, and said something along the lines of “we bought this and swear by it, if your kid really likes ‘X’ you should consider getting it because it has really helped our family.” These products were wide-ranging; chew toys or sensory toys, seats, swings, beds, travel equipment, books, TV shows, Autism t-shirts, organization materials, GPS trackers, safety equipment, pull-ups, and even certain foods, protein powders and protein shakes. This is a phenomenon that I would be curious to see further explored through research; are online support spaces more susceptible to this level of consumption and consumerism than in-person support spaces? Does this level differ between Autism parents and, say, Down Syndrome parents? Does this level of consumption and consumerism in these online spaces ever deter parents from remaining in these groups? Does it draw parents to stay?

For the rest of the categories, I will briefly discuss their general purposes within this online community. School system problems/questions usually regarded Individualized Education Plans (IEPs), the difficulties with standardized testing, and problems with school teachers either not understanding children, not treating them properly, or not communicating with parents well. As for information regarding systems, parenting and advocacy, these posts included links to webinars about parenting kids with Autism, events that accommodate children with sensory challenges, or favorite Autism charities and nonprofits to donate to or volunteer with. Poor provider interactions were talked about less than expected; the few posts talked about disagreeing with providers’ decision-making, complaining about providers pushing their own agendas onto that of the family’s, as well as children being treated poorly at therapy and lack of professionalism. Effects on other family members were posts regarding siblings, spouses, other immediate family members and even pets, particularly in how they are impacted by the child with Autism. There were stories of siblings being overshadowed or arguing with the child who has a disability, and as for spouses, there were many stories of unhappy marriages, discussions of high divorce rates, wondering about if they should have more children or not, or venting about spouses, particularly husbands, not pitching in enough or taking on enough of the care burden. Posts regarding barriers such as cultural, language, or economic barriers, included talking about not being able to afford certain services or products, lack of interpreter services in healthcare, and people of color not feeling welcomed by providers. Diagnosis experience posts included parents questioning whether certain diagnoses fit their children, and parents lacking information about waiting lists, what evaluations will be like, and how they can help their children during evaluations. There were also multiple posts in this category that included parents stating that they feel guilty after getting a diagnosis, either feeling like they didn’t catch the “problem” sooner or feeling guilty that their child has gone on this long without support. Problems with government systems included posts talking about Medicaid covering or not covering therapies or equipment, not being able to get caregiving hours covered by the state and not having enough help to get time away from children, and struggling with the healthcare system in regards to telehealth appointments during COVID-19. Many parents used this space to vent about the complexity of the systems they are forced to navigate for their children. Posts regarding seeking more parent support were generally parents looking for more support groups they could join, or worried about the quality and makeup of other groups that they were considering joining. Some of these posts also aimed to seek out parent mental health resources.

Two categories that were particularly intriguing were seeking friendship/connection, as well as caregiver mental health/burnout. To begin with posts regarding seeking friendship/connection, some parents posted offers to be virtual buddies or online friends via Facetime or Zoom, explicitly stating that they just wanted more friends who understood their struggles. Other parents posted about moving to new areas and looking for communities to join, and others just wanted to offer emotional support over direct messages if anyone was going through something particularly challenging that day. Some posts talked about discrimination and stigma, many regarding housing and living situations; these posts included parents receiving noise complaints due to their child's loud vocal stimulations. Others of these posts included not feeling welcomed at church as a result of their child having challenges, problems with extended family members using negative language around a child's disability, and general looks and stares at grocery stores or parks that parents get as a result of their child behaving in atypical ways.

As for caregiver mental health and burnout, there were different categories of posts within this general section that feel important to note. First, parents expressed guilt, either for cutting back on therapies because they are too expensive, or for not recognizing their child's differences sooner, stating things like "I don't think I'll ever forgive myself for not recognizing it sooner" or "we just found out my child has Autism and I couldn't control myself *crying emoji*... I feel guilty." Another category of mental health posts expressed anger and frustration; parents venting about how difficult it is to manage their child's behaviors, and one parent even expressing that she cries and cusses at God for doing this to her and her child. She even said that "sometimes in the deepest, bad moments of depression, I say to myself, why did we have another child?" Another category of posts expressed exhaustion and burnout, particularly with not having caregivers to help out or troubles with "spreading themselves" between multiple children. Another category involved self care, specifically lack of self care, where parents expressed that they lack sleep because they lay awake at night worrying about future years, parents stating that they feel like no one is able to help them, and even including funny, satirical memes about Autism moms not exercising, getting rest, or practicing self care as doctors ask them: "How are you?" One of these posts included a poll that was posted by a mental health clinician who is also an Autism parent, and she asked if people would be interested in semi-regular mental health-themed posts for managing stress, depression and anxiety. There were 126 votes for "yes please" and 6 votes for "no, keep it about our kids". The last identified category within mental health and burnout posts was posts expressing worry. Most of these revolved around parents worrying about their kid getting what they need, about how they are going to grow up, about how they will be cared for in the future, and worrying about discrimination and stigma they may experience as they get older. One parent in particular said: "Autism isn't easy. It's hard no matter what end of the spectrum your little one falls on. I have two littles on the spectrum and I'm scared every day. Scared for the future, scared of will they or won't they talk, will they survive on their own? What if something happens to me or my husband?!"

Overall, reviewing this online parent group provided endless insight as to the conversations and topics that these parents shared with one another, and also brought up many questions that need further exploration through research. It is also important to note that there were no posts regarding care coordination, patient navigation, or social work. None of these parents, at least within the two-week period observed, asked about these individuals "in the middle" of themselves and the healthcare system who could help. Next, the benefits and concerns to online support groups will be discussed. The benefits and concerns to support groups in general still apply to these online spaces, although online support brings unique challenges and rewards to families that must be discussed in their own context.

Benefits of Online Parent Support Groups

Beyond the many benefits of disability parent support groups as outlined previously, online groups can offer unique benefits to disability parents that in-person groups may not be able to provide. Two specific benefits of online groups, beyond those already discussed, were identified through this research and spoken upon in interviews. The first benefit is that with online groups, parents can connect with one another based on very rare, niche diagnoses, and can connect with specific populations worldwide. One of the providers interviewed explained that on her caseload of patients, the majority of them have a "rare genetic disorder of some kind that basically no one else has. One of my patients has one other person in the country that has the same thing, and then the only other person in the whole world is a child in Ireland, and they send each other messages and gifts and things." The benefit to online spaces is that families can connect with others who understand their experience, despite being very far away from one another. Online spaces provide these families with the opportunity to find their specific communities, because without the ability to connect online, these families would otherwise have no one.

The second unique benefit of online parent communities, beyond those previously mentioned for parent support groups in general, is that online spaces are great for families with limited time. These spaces are generally easy to "pop in and out of", do not require a time commitment, and can be utilized at any point of the day. Parents can post or read whenever is convenient for them, which as outlined previously, can be incredibly helpful for these very busy families. One of the navigators spoke on this benefit: "I think online groups are great resources for families who have limited time or want to just jump in and look at chats when they can, because there's really not that much commitment in those spaces." Overall, online groups provide families who are limited on time or on communities that reside close to them an opportunity to connect with one another, and to enjoy the same benefits of support groups outlined previously.

Concerns with Online Parent Support Groups

While these online communities offer unique benefits to parents, there are also quite a lot of concerns with online parent communities that may at times outweigh the benefits they can receive from online support. In this research, it became apparent that online communities present many more risks and challenges than in-person parent support as a result of residing online. The first major concern voiced by those interviewed was that these online communities often spread misinformation to disability parents, and this can be incredibly dangerous and harmful for newly diagnosed families who are still in the learning process. One of the patient navigators and support group leaders said that if she felt that these online communities were good quality and she felt comfortable about what was talked about in those spaces, that she would probably suggest them more, but she explained her hesitation:

> "It just makes me kind of nervous that online groups may go into a deep, dark rabbit hole and I don't want families to experience that. I think informing them of the risks is important, again, it's all about helping families be aware and advocate for what they feel is right. It is scary to think about offering online communities to families that are really isolated because you don't want them to find a community that is not a good fit or is going to misinform them of everything."

One of the healthcare providers interviewed explained this same hesitation around recommending these online spaces, as she has had families harmed in a specific manner by these spaces:

> "There's all of these sort of charlatan, you know, people trying to make a fast buck on 'lotions and potions' and things like that, and they say 'spend a thousand dollars on this thing and it will cure Autism', and families will invest what little money they have in this thing that is not going to work because they are uneducated, and it's that kind of stuff that is a huge barrier to those groups."

Beyond the spread of misinformation, online parent communities can often be untrustworthy spaces of support due to lack of proper facilitation. When it is unknown who is monitoring these groups to ensure they remain safe spaces, there is a much higher likelihood that they turn to unsupportive spaces or not disability-positive environments, which is incredibly harmful for parents but especially can be harmful for children with developmental disabilities. One of the providers interviewed explained that because Facebook has "exploded with groups that are supportive and groups that are not, it becomes really scary." She explained that the key is that families find a group of like minded individuals, and if they do, she guesses that this can be very empowering and beneficial in terms of advocating for their children. But on the flip side, she explains that "if they get in with the wrong one, then they feel kind of defeated and they aren't supportive for them. Social media is just a little bit scary out there." Another provider mentioned her hesitancy to refer families to online groups for this same reason; she explained that because she doesn't know who is monitoring these groups and doesn't see the day to day kinds of conversations that happen, she fears that they may not be the most helpful for families. This concern with online communities is incredibly significant, as this opens the door for harm in a very large way.

Online parent communities can also be untrustworthy in the sense that they can often contradict what the healthcare community knows to be the most effective way of supporting children with developmental disabilities. These communities can be unsupportive of what we know, through science, to be the most efficacious way to support children with developmental disabilities. This can be really harmful for parents who follow what their healthcare providers say and are judged for it as a result, but can also be really harmful for children with developmental disabilities whose parents are swayed away from doing what is medically and developmentally appropriate for their children. Oftentimes, parents can be heavily swayed by these groups, at times turning away from therapies that could be really beneficial for their children with developmental differences. The most prominent example shared throughout this research was that of Advanced Behavioral Analysis therapy for individuals with Autism Spectrum Disorder, due to the controversy with ABA therapy in recent decades. One of the healthcare providers interviewed explained how this controversy can cause harm in these online spaces:

> “In the Autism community, there is a big movement right now, a lot of pushback from adults with Autism, that are criticizing Advanced Behavioral Analysis Therapy and criticizing parents of kids with Autism for pursuing ABA. So there's also that push-pull that I think can lead to a lot of conflict for parents to be dealing with the emotions of having a child be diagnosed and trying to weigh the pros and cons of things that are recommended, and then getting on the internet and seeing all this criticism puts them in a place of doubting. Doubting their instincts, doubting me; it's pretty counterproductive. That being said, I do absolutely think there's important things to learn from adults with Autism and I think that the neurodiversity movement is really really helpful and important, but I think it also can be a little damaging in some of these online support spaces when we know that ABA therapy has since changed and is the most effective way of supporting individuals with Autism in a disability-positive way.”

Doubting the efficacy of medical interventions that are proven to be supportive of individuals with developmental disabilities, when done properly, can be incredibly harmful for children themselves. This concern around online parent support communities is the most prominent reason why the healthcare professionals interviewed said that they are hesitant to suggest online support communities, and this is a very significant risk factor for harm to be done in these spaces.

Another large concern with online communities is that not all individuals have access to technology that enables them to access these spaces, and even when parents have the technology to access these communities, there is a safety risk to online support. As for the technology barrier, one navigator explained that for many groups that she knows of, they say “all you have to do is email this person or call this number” in order to join the group, but sometimes families, who could really benefit from support, don’t have easy access to phones to make calls or computers to send emails. The safety risk online is primarily in regards to confidentiality; online communication in general can bring a significant risk to families, especially when discussing personal information about their family members and specifically their children. One of the providers interviewed mentioned the question: “How will your kids feel once they turn 18 and their personal information, information about their health and their specific challenges growing up, have been shared with thousands of people, and won’t go away?” Pictures, videos, and stories of their children are often shared with thousands of individuals, and beyond the concern with consent, these can be screenshotted, saved, and shared in many different ways to be seen by many different viewers, and this poses a huge risk to parents and their children.

The last concern that is of noteworthy mention as a result of this research is that despite the benefits of online communities, there is still some degree of isolation within these spaces. One of the parents interviewed explained that she did not pursue online support groups, despite trying them, because “people are just isolated. A Facebook group of moms who ‘get it’ versus going to dinner with a bunch of moms who ‘get it’ are two totally different ball games.” In our world today, we are increasingly isolated by our technology, and in terms of building community and accessing support networks, online spaces fail to offer the same level of connection as in-person spaces as a result of their nature. Overall, online communities, while providing a means for parents to connect with one another with more ease than in-person interactions, present many risks to families which must be taken into consideration as families seek support in these spaces and as we make recommendations for families to access support networks to learn how to navigate the healthcare system.

Washington State and Important Intersectionalities

Well-working parent-professional relationships are critical for achieving successful outcomes of children with developmental disabilities, but often intersectionalities such as race, cultural background, socioeconomic status, and gender make adequate parent-professional partnerships harder to achieve (Jegatheesan, 2009). As already discussed, any parent with a child who has a developmental disability faces many challenges in their relationships with the healthcare system and with individual healthcare providers. These interactions and experiences are even more fragile when cultural differences exist between families and providers; cultural differences often lead to lack of understanding for both parties, parental lack of confidence and trust in providers, and therefore undermining the opportunity for true partnership between parents and providers. When a partnership cannot be achieved, shared goals cannot be met and outcomes for these children suffer in consequence (Jegatheesan, 2009).

Culture can contribute greatly to a family’s ideas and beliefs around disability, and can impact the ways in which families navigate care for their children with developmental disabilities. One study conducted through the University of Washington revealed that Asian American mothers in Washington endured significant difficulty in navigating the healthcare system for their children with developmental disabilities due to issues with communication and strong cultural barriers existing in the Puget Sound area (Jegatheesan, 2009). Disability and diversity is argued by Jegatheesan to be a double-edged sword; in the context of Asian-American families in Washington State, families face social, cultural, and linguistic barriers as well as hold unique religious and cultural beliefs around having a child with a developmental disability. On the one hand, negative beliefs exist such as parents being punished by having a child with a disability, versus the positive beliefs, such as parents being blessed and having been given a gift from God by having a child with a disability. Negative beliefs held by these parents may contribute to parents being deterred from candid conversations with healthcare professionals, leading to parents deciding against seeking further services. Positive beliefs can contribute to resentment of healthcare professionals, as some professionals hold discrepant views of these children with developmental disabilities (Jegatheesan, 2009).

Recommendations by Asian-American mothers in Washington State for healthcare providers focused on three major areas: increasing quality and prevalence of competent interpreters, increasing provider understanding of Asian values and cultural customs, and ensuring that professionals have greater compassion, patience, and respect for families with cultural differences who are going through the process of raising a child with a developmental disability (Jegatheesan, 2009). In the early diagnosis and post-diagnosis period, families formulate culturally diverse conceptualizations of their child's disability, and these conceptualizations impact the family-professional dynamics in cross-cultural encounters when seeking healthcare services for their children (Jegatheesan et. al., 2010). One form of cultural competence is having an understanding of a specific family's reliance on social supports, such as family and community in their experience raising a child with a developmental disability. Families situated at intersectionalities with race or cultural background have unique cultural lenses which are usually different than that of most healthcare professionals (Jegatheesan et. al., 2010). It is essential that we increase the cultural competence of healthcare providers and parent support organizations serving families who have a child with a developmental disability in addition to some other form of intersectionality that predisposes them to strained partnerships with healthcare providers and support organizations.

The prevalence of developmental disabilities is rising, in part due to greater recognition of developmental disabilities but also as we work to better include minority populations in diagnoses and therefore healthcare services and social supports (Zablotsky et. al., 2021). From 2009 to 2017, the prevalence of any developmental disability increased significantly, by 9.5% (Zablotsky et. al., 2021). This means that between this time period, approximately 1 in 6 children (17% of children) in the United States were reported to have a developmental disability diagnosis (Zablotsky et. al., 2021). This growing population of individuals diagnosed with developmental disabilities is going to need to be met with greater services and supports moving forward, and this applies to the state of Washington. In terms of intersectionality, as more diverse populations of individuals with developmental disabilities rise, we must ensure that healthcare providers and parent support organizations are culturally competent in working with diverse families to serve children with developmental disabilities in our state.

It is also important to note that the Developmental Disabilities Administration (DDA) of Washington State, within the Washington State Department of Social and Health Services (DSHS) serves populations uniquely based on many factors, and intersectionality can be understood better by looking at some of the current data produced by the WA DDA. In 2020, 54.3% of families who were eligible for DDA support were white. The most concentrated counties of individuals with developmental disabilities who are being served by the DDA are King, Pierce, and Snohomish counties, with King County having the highest numbers of individuals served (6,818 children and 6,267 adults) (Developmental Disabilities Administration, 2020). It is important to understand that the majority of families with the greatest access to services in Washington State are white, middle-class families, and this is not necessarily representative of the true population in need of these services for their children with developmental disabilities. In the following sections of this thesis, barriers to navigating the healthcare system successfully, as well as barriers to accessing parent support services in Washington State will be discussed based on conversations in interviews. Intersectionalities cannot be excluded from navigation and parent support discourse in the context of Washington State, and in order to support families of all backgrounds in navigating and in community, we must discuss the ways in which some groups are disproportionately affected by the challenges of accessing services for themselves and for their children with developmental disabilities.

Economic Barriers to Navigating the Health System

Families who are disadvantaged in terms of economic status face a much greater challenge in navigating the healthcare system for their children. One of the navigators interviewed discussed supporting families who are of very low socioeconomic status: “I can give all of the encouragement in the world, but if they don’t have food to eat then really, it’s not the time for encouragement or navigation support, they just need food.” When families are unable to meet basic needs or do not have the financial resources to support their family’s general wellbeing, navigating the healthcare system for a child with a developmental disability is placed on a backburner as a result of lack of capacity. Therefore, families of disadvantaged socioeconomic statuses have a near impossible, if not impossible job of navigating the healthcare system for their children. From affording medication or therapies that Medicaid may not cover, to not being able to afford transportation to medical appointments, to not having access to a reliable phone or internet, some families simply are not given the support they need to attempt to navigate the system, yet alone actually become successful in maneuvering. One of the patient navigators interviewed explained that many parents have multiple kids that they are watching over, they don’t know how to use the bus service to get groceries yet alone get to medical appointments, and they don’t have daycare services available to them. Not only do some families lack access to the tools that enable them to ATTEMPT to navigate, but families that may have phones or transportation who are still of low socioeconomic status still may lack the ability to access quality services for their children based on income and insurance. Even families who have the tools necessary to begin trying to navigate the healthcare system are unable to successfully navigate if their insurance or Medicaid does not cover what they need. One of the providers interviewed explained the economic disparity in accessing forms of care for children with developmental disabilities:

> “The economic disparity is a huge disparity for this population - it’s different from a lot of medical diagnoses because if a child needed an expensive medication for example, Medicaid would pay for it. I don’t know that there are other things than a diagnosis of a developmental disability that involve such life-altering conditions, that parents have to move mountains to have it happen for their kids. And there’s just factors in your life that sometimes you just have no control over; you cannot just change insurance plans for example because you would have to stop working to get a different job and then the other two kids you have won’t eat… I mean it’s just sad and there’s nothing the state is doing about it to change what these families go through.”

Beyond just the fact that these families are often unable to afford services for their children due to lack of financial resources through insurance or Medicaid, the families that can manage to afford these services often are left with therapy centers that are of less quality than families who can afford private therapies for example. There is not only a barrier in terms of having the tools to navigate, there is not only a barrier in terms of the options available to you as you navigate care, but also, if you are from a disadvantaged socioeconomic background, you are often left with lower quality care as well. This exacerbates the disparities that these families face, and ultimately the people who pay the price in these disparities are children with developmental disabilities from disadvantaged backgrounds. Children born to families of higher socioeconomic status have a higher chance of reaching their full potential as a result of navigation than families who are not as financially stable. One of the providers interviewed explained this simply: "unfortunately, there is a huge disparity based on income and insurance for what services, and the quality of such services, to children that get a diagnosis of a developmental disability depending on their insurance and family income." Overall, disability parents who are from lower socioeconomic statuses face an even greater challenge than the average disability parent in doing what is best for their children with developmental differences, and this disparity and barrier to navigating the healthcare system cannot be forgotten as we approach systemic change to alleviate the burdens these families face.

Economic Barriers to Accessing Parent Support

In the same way that economic barriers impact parents from successfully navigating the healthcare system for their children, these same challenges that families of low socioeconomic status face apply to accessing parent support networks. While some organizations do a great job of reducing these barriers for families by providing free services to parents as they access support groups, there are still challenges for families in accessing this support if they do not have access to a phone, a computer for Zoom or other forms of video conferencing during the COVID-19 pandemic, or transportation to get to a support group meeting. Online groups can be an option for families who lack transportation, but there is still a technology barrier for low-income, disadvantaged families. If these parents cannot navigate the healthcare system successfully, and cannot access parent support networks that can help them, they are left helpless when it comes to maneuvering through systems for their children with developmental disabilities. Disparities based on socioeconomic status are of critical consideration in examining how to best alleviate the burdens that parents face in navigating the healthcare system for children with developmental disabilities.

Language Barriers to Navigating the Health System

Time and time again in interviews, parents, providers, navigators, coordinators, and support group leaders all spoke on the language barriers that non-English speakers or bilingual speakers face in terms of navigating the healthcare system for children with developmental disabilities. To start with the language barrier in healthcare visits themselves, families who require translator services, when it comes down to it, are given half of the amount of time that English-speaking parents are given in a healthcare visit, as a result of translators repeating what each person said. Beyond the time that is stripped from these families, translator services often lack in quality, and also, are oftentimes unavailable to families and providers. Some medical terminology, specifically regarding disability and developmental disabilities, often do not translate directly at all to other languages, and as a result, there is miscommunication about vital information regarding a child's health. Interpreters also often do not directly state the exact same thing that parents say or that providers say, and this can be incredibly confusing, frustrating, and scary for families as they are trying to communicate with providers about their needs and what is best for their children. One of the parents interviewed, who speaks both Spanish and English, talked about her struggles before she was fluent in English in terms of relying on interpreters as her child was being diagnosed:

> "Something I discovered is the lack of communication is a huge component, because the providers, most of the time don't provide interpreters, and if they do, they are not qualified, they are not certified, or they are not familiar with the vocabulary. For example, the vocabulary in the school system with special education or with developmental disabilities. And depending on the organization, it seems like there is not a lot of support for interpreter services. When my son was being diagnosed, I had a personal experience with interpreters because for me, it was so hard to learn English. I was in school for 5 years in ESL (English as a Second Language), and I always came back home in tears because it was so hard, but once I did start understanding, I discovered the interpreter wasn't saying what I was saying or exactly what the professionals told me. And I was surprised, because I was like 'this time I was saying this and it wasn't like that' or 'that time they were saying this', and I was in shock."

Beyond the fact that these families are scared and lacking trust in interpreter services as they approach very real and serious conversations regarding their child's health and well-being, some of these families, as explained by a support group leader, even speak another native language that is outside of a mainstream language. She used the example of families who speak another native language who are from Latin America, so Spanish is their second language, and then they are trying to understand interpreters from English to Spanish, which is already a challenge for them. Families who speak multiple languages, no matter the circumstances, are forced to navigate a challenging, confusing system for English-speaking families, with even greater hardship, confusion, and difficulty.

Beyond healthcare settings, non-English speaking parents are left to try to navigate the system for their children with even less tools and resources. One of the providers interviewed explained how difficult it can be for these parents:

> "It is excruciating how difficult it is for parents who don't speak English, who have to rely on translators to understand and communicate about such an important thing, for the diagnosis, and then have to go out in the world and have to try to navigate it on their own is really, really… that is the number one barrier I would say. How are families supposed to do it? They can't."

As families attempt to navigate the healthcare system outside of their healthcare visits, it becomes near impossible for them to understand how to apply for programs like DDA, or to learn how to make phone calls to get on wait lists for therapy centers. One navigator explained that if families need to look up something online that is only offered in English, or if families are trying to send an email and they don't know how to write in English, they do not even have the opportunity to try to get care sorted out for their children. They don't even have the means to communicate that they need something that is critical for their child's wellbeing. Another navigator explained that many therapy centers may not have any interpreter services, and so these families are left in the dark and their options for care are significantly decreased from those who speak English. She echoed the same thing as the previously mentioned provider: "that is the biggest barrier for families by far, language." One healthcare provider interviewed explained the impact of these decreased options for families who do not speak English, and how this greatly exacerbates the inequities these families experience: "The parent's ability to navigate the system is quite important for their children's development, which unfortunately creates a divide because the English-speaking, savvy families basically end up with better care because of their ability to navigate, which is wrong, and doesn't feel good at all." Overall, families who do not speak English or do not speak fluent English in Washington State are eventually left with lower quality of care for their children with developmental disabilities than those who can speak English. The impact of language on a family's ability to navigate the system, solely based on the lack of support offered by the system, is critical to understand as we approach alleviating the burdens families face in learning how to maneuver through the system and provide the best possible care for their children.

Anecdote - The Harmful Impacts of the Language Barrier

One of the disability parents interviewed shared her story as a Mandarin-speaking parent and Chinese immigrant as her child was diagnosed with Autism Spectrum Disorder. She spoke about the harm that was done to her family during the process of getting a diagnosis, and the massive miscommunications that ensued along the way. To begin, her child's primary care physician gave them the Autism screening for young children, called the Modified Checklist for Autism in Toddlers (MCHAT) at one of her child's early check-up appointments:

> "I just briefly went through this questionnaire, I didn't read very carefully, I saw the question 'Can your child walk?' So I thought to myself, 'that's a very simple question, seems like it's not a problem'. So the doctor didn't tell me that it is very important for your child to do certain things, and these can be early signals that maybe indicate Autism or disabilities or developmental delays. So nothing from the doctor indicated that time was a VERY IMPORTANT phase of evaluation, so I totally ignored it. My older child's early check up went totally smooth in China, so I didn't realize that my second child might have some problems, but when the doctor said 'okay you can go to Kindering' [Kindering is an Early Intervention Agency for children with developmental delays that screens for Autism], she didn't say that your child might have some delay or Autism. She didn't communicate that at all. So I brought him to Kindering to go through with his evaluation; I wasn't told by them that this was a very important evaluation, a very critical phase for him, I didn't even realize that Kindering is a clinic for children with special needs, so in my mind, I didn't do any research or any preparing about disability, I just thought 'okay this is my second child and I have experience raising them and feeding them and everything'. So when Kindering referred me to an Autism evaluation, I thought to research 'What is Autism', I watched a video on Youtube and my husband did a lot of research too, and we saw that Autism seemed like a very terrible thing, that adult Autistic people are just totally different from our people, that it would be a really big

> challenge for his life and also our life. We were totally shocked and it was very, very scary."

Not only did miscommunication start at the level of the primary care physician, not only was the purpose of the screening tool miscommunicated, not only did miscommunication continue into being referred to an Early Intervention agency, not only did it continue on through the evaluation through the Early Intervention agency, but only when this family was finally referred for an Autism evaluation explicitly did they receive the message, based on their own personal research, that their child may have some sort of developmental difference. These parents were left in the dark all the way through, until it was shocking that their child was receiving an evaluation for a lifelong developmental disability. This parent's story summarizes how much can go wrong, even as we screen for developmental disabilities and utilize interpreter services, if parents are not being communicated with thoroughly enough. If this mother had spoken English, so much of this confusion, miscommunication, and harm could have been avoided, and to be very clear, this is no fault to individuals who are non-English speakers, but rather a massive failure of our system to accommodate individuals who communicate differently than the norm.

Language Barriers to Accessing Parent Support

Just as language was identified by research participants to be the biggest barrier to navigating care, it was also echoed to be the biggest barrier for families as they seek out parent support groups. As non-English speakers seek out parent communities, it is not frequent by any means that these groups and organizations have the ability to provide interpreter services. Beyond the logistics of joining groups by making calls or sending emails in English, non-English speaking parents often cannot even sit in a support group if everyone is speaking English. On the rare chance that interpreters can be provided within a support group, families may feel that they are taking up too much time by using an interpreter to communicate with other parents. Even online spaces are English-speaking, and reading and writing in English is often not an option for these families. One of the patient navigators and support group leaders interviewed explained that not only is it challenging to utilize interpreter services for communicating in parent support, but there is also a loss of emotional connection as a result of interpreters that occurs:

> "I speak a lot with non-English speaking people. I have a love-hate relationship with interpreter services - we use the language line, and I am so glad to be able to help them, but I just feel like I am being so unhelpful at times because you can't provide emotional support through an interpreter, through a phone line, it just feels so impotent. It usually ends up being that we only provide them with logistical support, and they can't receive any sort of emotional support or sense of community."

Not only do non-English speaking disability parents struggle to access these groups, but even if they do, they lack the same ability that English-speakers have to connect with others, to build community, to offer and receive emotional support, and in turn, these families lack the same access to these parent support networks that serve as helpful in navigating the system for children with developmental disabilities.

Cultural Barriers to Navigating the Health System

There are many cultural barriers that prevent people from navigating the health system successfully for their children with developmental disabilities. Some of these barriers involve disability stigma based on cultural background, and others involve fear of accessing services or fear of discrimination based on one's cultural or ethnic background. For the purposes of this research, these two categories of cultural barriers will be discussed, although there are many others in which can be explored. Included in this section is discussion of the differential treatment of parents and families who are people of color, and how, based their cultural backgrounds, justifiably fear discrimination and maltreatment from the healthcare system. To preface, this summary of what was talked about in the interviews conducted will be far from comprehensive of all cultural backgrounds and the unique challenges they face in regards to the intersections between their culture and disability. This information cannot be generalized, and what is most important to note is that some families who identify with other cultural backgrounds besides white, heterosexual, cis American culture, often face a unique hardship in navigating the healthcare system. From my perspective, their voices need to be amplified as we address the problem of helping parents learn to navigate the health system for their children with developmental disabilities. This research is speaking on these challenges in order to express a need and desire to learn more about the unique experiences of these families, and does not mean to make assumptions about their experiences, but rather give voice to those that were heard as a part of this project.

To begin, one category of cultural barriers that were addressed was that often, on the basis of cultural background, some families may hold strong ideas of disability stigma that prevent them from successfully navigating the healthcare system for their children with developmental disabilities. Based on these stigmas ingrained in cultures, parents may have conceptualizations about disability and how it should be addressed that conflict with the ways in which westernized healthcare supports and treats individuals with developmental disabilities. One of the patient navigators, who works with many multicultural families who have children on the Autism spectrum, discussed how cultural background and disability stigma can play into the ways in which families approach care for their children, and how it impacts their ability to navigate the system:

> "Many different cultures that I work with have a lot of stigmas, specifically around Autism, and so it might take a long time for a family to come around to understanding Autism or to being open to an evaluation, and even if they do get evaluated, there is lots of miscommunication and misinformation around Autism, like thinking you're going to be cured or that this isn't going to be a thing their whole life. They sometimes think that in their home country, there is 'no such thing as Autism', so if they were there they wouldn't be Autistic, so there's really just all these interesting things that I've heard. So there's a cultural piece of misinformation and stigma and judgment that comes with a lot of families. And then a lot of times, families have recently immigrated, so they don't have any community, they don't have any family here, so they are really isolated, home alone, they don't have people to support them, and they are

> pretty lost when they are trying to navigate any of these systems, especially with the cultural beliefs they hold."

Some examples of what this navigator spoke about, in regards to hesitations about navigating care and miscommunication based on cultural stigmas, include struggling to educate themselves and extended family members about developmental disabilities, and what that means for their children. The Chinese, Mandarin-speaking parent I spoke with mentioned that her and her husband read many Chinese books about Autism, and gave them to their extended families to read so that they could understand their child's needs better, and mentioned that "because people only see disabled people in China who only look disabled or different, they could not understand why our child is disabled because he looks very normal." She also mentioned that in Chinese culture, "there is always a saying that 'the people that talk late will always be smart', meaning they are smart so they talk late, so they don't realize that our child has a communication problem because he is Autistic." Along these same lines, one of the navigators who works out of an early intervention agency spoke on the challenges of delivering therapies, specifically in-home therapies, to families of diverse cultural backgrounds, as some of the protocols of therapies conflict with cultural beliefs:

> "I would say some Indian, but more Taiwanese and Chinese families, often have their moms [the child's grandmother] come and stay with the family for a while and the Advanced Behavioral Analysis therapist comes in and pushes the kid to ask for what it is he or she wants to practice communicating their needs, rather than just be given what it is that they want based on assumptions, but the kid is crying, so the grandma says 'you're out of here' because it conflicts with their cultural norms. So there's all kinds of cultural norms that go on and we have to be so much better about them and need to understand them so much better than we are right now in order to properly accommodate these families."

Overall, cultural norms, stigmas, and values all very much play into the ways in which families approach care, and oftentimes, with the way our western healthcare system is set up, these beliefs prevent families from accessing care, as there are no options of care that properly accommodate their culture. As a result, families of diverse cultures have a harder time navigating the healthcare system for their children with developmental disabilities as a result of their predisposing ideas of disability and the ways in which their children should be cared for.

The other form of cultural barriers that were identified through interviews was fear of discrimination or maltreatment on the basis of one's cultural background that prevents some parents from navigating the healthcare system successfully. This could also include cultural backgrounds that value professionals so heavily that they feel that they cannot question or go against the recommendations of healthcare providers. As an example, one parent interviewed explained her upbringing and how it, at first, prevented her from advocating for her child in the way that she wanted to:

> "As a Latino, we are raised to believe in the professionals. We believe they are the best, they know everything, and we highly respect them because they are the professionals and they have a title. My dad and my mom raised us very well, that we are supposed to respect professionals and also elders. And the doctor that I was working with at that time was also older

> than me, as I was young at the time. And I was like ‘that’s so weird’ during the visit, but I didn’t ask anything. I was thinking in my head, ‘I have to respect the professional, he knows best’, and also the interpreter was older than me, so it felt like these are people I have to respect no matter what. And so I didn’t know how to advocate for myself and my kids at that time. I didn’t know the system, I didn’t know how to speak up because of hierarchies and also because of the cultural barrier, and so it was really hard.”

Other forms of fear of discrimination or maltreatment can come from a mistrust of the healthcare system based on one’s cultural identification. It was explained by multiple healthcare providers that cultural competency is something that they wish they knew more about and could have more training around, even if they had already learned about it extensively. Some families, and with full merit, are terrified of the harms that have been done to people of their cultures in the past, and as a result, hold a mistrust of healthcare. This could be based on very real consequences of accessing care, or based on passed down stories of maltreatment. Either way, as a result, this fear of discrimination and maltreatment can be a very significant factor as to why families struggle to pursue healthcare navigation for their children with developmental disabilites, as their utmost goal is to protect their children from harm. One clear example of this shared by a navigator interviewed, in regards to families that may have very real consequences for accessing forms of care, is some families in the Latino community:

> “The backward slide I have seen over the past five years is that things have gotten even more rough for the Latino community, things have always been really rough for the Latino community, but the past few years have especially been bad because they are afraid that if the came and got help for their kids, they were going to get deported. And that just hurts my heart so bad. I cannot even imagine what that would be like.”

What it comes down to for these families, in any situation where they may feel that they cannot access healthcare based on their cultural backgrounds, is that they face a decision between getting help for their children with developmental disabilities and possibly facing devastating family consequences, or choosing to protect their families by not seeking help for their children. And many of these families, respectfully, choose the latter option. Cultural barriers are some of the most significant barriers that disproportionately affect families of disadvantaged backgrounds from navigating and accessing healthcare for their children with developmental disabilities. Different cultures, and their respective beliefs and values, must be better understood to accommodate families in navigating healthcare and supporting their children who have developmental differences.

Cultural Barriers to Accessing Parent Support

Just as cultural backgrounds influence the ways in which families can access care or may feel comfortable or uncomfortable accessing care, this same barrier can influence, in similar ways, how families are able to connect with parent communities and support organizations. What feels most important to discuss in this section is the struggles that families of color face as they try to access support networks. It is hard to feel supported and included in these communities when the majority of the individuals that participate in them do not look like you. This was highlighted by multiple research participants, one of which was a healthcare provider who spoke on the multiple layers of stigma that families may face when they fit into the "disability bucket" as well as the "people of color" bucket:

> "Some families deal with a layer of stigma having a child with a disability, and for some families such as families of color, where they deal with the stigma of a disability and then on top of that, the racism that goes on with being a person of color is an additional layer of discrimination that they experience. I think sometimes in support groups, especially in Seattle, it can be very white, English-speaking, and middle to upper-class, and so I could understand why families of color don't feel as comfortable in those situations because again, the whole reason you join a support group is because you want to be around people who 'get it', and sometimes, I think families of color don't necessarily feel comfortable in the very white and very affluent support groups."

To combat this feeling of isolation that families of color and families from diverse cultural backgrounds may experience in terms of accessing support, one provider spoke about her personal mission of connecting families to one another who are from similar backgrounds. She worked with a Chinese client to connect newly diagnosed families to a group of Chinese parents, and has worked with other groups to try to build communities of people that are of similar cultural backgrounds: "I want to be a matchmaker, I want to try to find ways to connect families from those communities so they have somebody to talk to about their experience that might understand them more than a bigger support group would." Despite providers, support group leaders, and disability parents trying to organize niche groups of people that can connect on cultural levels, it is still very difficult for families of diverse backgrounds to find these pockets of like minded people, and as a result, when they seek support from general disability parent support spaces, they often feel like outsiders in a group meant to bring people together. One of the healthcare providers also spoke on this issue:

> "When we think about the American, what we consider to be the American, racist culture, which is a white culture, a white hetero culture, a white, cis, hetero culture, accessing support groups for any individual that identifies different than that is a challenge. In terms of identifying a group that is representative of the whole population of people with disabilities, which is not a population that is cis, hetero, and white, it becomes even more difficult. I think a white family does not have the same perspective as a family that does not have those same resources and privileges available to them."

Overall, the importance of considering the cultural backgrounds of individuals as parent support organizations make their services more representative and inclusive cannot be stressed enough. Making these spaces more inclusive and equitable will work to reduce the disparities these families already face in navigating care, as they will be able to access support networks in which they can rely on other parents of many backgrounds to learn how to best approach supporting their children with developmental disabilities.

Proposed Suggestions for Assisting Families in Navigating the Healthcare System for Children with Developmental Disabilities

Conducting this research has led me to propose suggestions as to how we, as a healthcare community, can work more in unison with the disability parent community in order to support the needs of these families, particularly in the early stages post-diagnosis in which they are learning how to navigate. Beyond such suggestions, I have also come up with some calls to action for specific entities that are large contributors to the struggles these families face as they try to do what is best for their children.

This project is intended to bridge a gap between the healthcare system and the disability parent community. The hope for this research is that the healthcare community can see the vast potential of parent communities in teaching newly diagnosed families how to navigate care for their children, and hopefully utilize these parent support networks in order to connect families with resources from the point of diagnosis. This hope and this focus still remains after conducting this work; there was a call from disability parents and parent support group organizations to connect the power of the disability parent community with the healthcare system in order to work together to support families who receive a diagnosis. One support group leader and parent emphasized that her hope for healthcare providers and disability parent support organizations would be to be on the same page in terms of resources to provide to families in the work that they do. Parents have shown resilience to the difficulty of navigating the system by establishing support communities, and if healthcare providers can at least be aware of the places that they can send families for support in navigating the system, some continuity can be established between the work of healthcare providers and that of disability parents and support organizations.

In order to connect the disability parent community and the healthcare community in Washington, specifically in the Seattle area, I will be presenting this research to both sides. So far, I am scheduled to present at the University of Washington Undergraduate Research Symposium, at the University of Washington Center on Human Development and Disability, the University of Washington Autism Center, Seattle Children's Hospital in the Neurodevelopment Clinic, and possibly at a state-wide Parent to Parent conference for support group leaders. Presentations to clinics will largely focus on the power of these parent communities, the factors that may prevent some families from accessing these communities, and the possible risks that providers should be aware of before they send families to receive services from various forms of support. Presentations to support group organizations will largely focus on how to make these spaces more equitable for all, on how these spaces can be utilized to help parents navigate healthcare for their children, and suggest reaching out to providers to form trustworthy bridges for swiftly connecting newly diagnosed families with supportive communities. My sincere hope is that more opportunities to present this work over the course of the next year will arise as this research is seen by more individuals who are affected by these issues. I am hopeful and confident that these presentations will be enlightening for both providers and parents, and that these conversations will spark learning, curiosity, and brainstorming into how we can work in unison more effectively.

Beyond my own presentation of this research, I want to propose calls to action for certain entities that can also help to bridge this gap between healthcare and the disability parent community. Throughout the course of this project, it became apparent that one way to help families learn to navigate, that has already been put in place, although currently lacking in efficacy, is the potential of care coordination and patient navigation. These individuals serve families in the “middle space” between the healthcare community and the disability parent community. The first call to action, therefore, is not only to increase the number of care coordinators and patient navigators, but also to create a formalized and efficient system in which these individuals are supported for their work and compensated properly for the difficult jobs that they do. Maybe this formalized system can be a government-run system, in which the state provides a coordinator or navigator to a family when they receive a diagnosis, and this person reaches out to families initially, checks in on them to see what they need help with as they learn to navigate the system, and is one, specific, consistent person who families can go to when they need help. Even if this state service was only provided for 6 months at the start of a family’s journey in navigating, I believe that this formalized system, providing families with one person that they can go to for help and resources, would be incredibly beneficial for their success in navigating the system earlier on. Families should know who they are supposed to go to for help, know who it is that will help them with paperwork or getting on a wait list or figuring out how to apply for DDA or SSI. Increased support from the state system itself would be my suggestion for improving the promise and efficacy of care coordination and patient navigation.

Next, a call to action for disability parent support organizations and to the disability parent community as a whole, would be to improve facilitation, accessibility, and inclusivity of parent groups and communities. If all parents are to benefit from the potential that parent communities have to offer, these spaces need to be truly welcoming for people of all backgrounds. There also needs to be greater representation in parent support organizations, particularly in leadership roles, so that there can be groups set aside specifically for marginalized groups to connect with one another, led by someone who fully understands what they go through as a result of the dual stigmas they face. These groups need to be facilitated by people who ensure that they remain safe spaces for all; one of the support group leaders interviewed explained the importance of setting the tone that “advice is only given when asked for.” I think that this is an incredible rule-of-thumb for parent support spaces to adopt to ensure that they are genuinely supportive and respectful of the unique challenges that individual parents face. Last, the need for groups based on language cannot be expressed enough, as well as the importance of providing interpreters to non-English speakers who wish to join groups. It also cannot be forgotten, especially in the era of COVID-19, that some families do not have access to modes of video communication in which many groups reside, and so supporting these families in their pursuit of parent communities will ensure that equitability is closer to being made reality.

The next call to action I will make is in regards to the perception of the Washington State Government, specifically in the ways our state supports both individuals with developmental disabilities and their families. To begin, as a developmental disability caregiver employed by the state through DDA, I have seen, experienced, and understood the system in which families receive caregiving hours. State hours pay caregivers significantly less than the private market pays caregivers; I have experienced this myself in switching away from families who I hold close to my heart, simply because their state hours do not pay me well enough, and opportunities for private caregiving often are willing to pay double, if not more than double, what the state offers to pay. As a result, families who access state care hours through DDA are left with lower quality caregivers, that is if they can actually find caregivers to work for them, which again, greatly exacerbates the inequalities experienced by marginalized groups who cannot afford to pay caregivers privately. The demand for caregivers is incredibly high, but the job can be challenging and emotionally-exhausting, and beyond that, the state does not pay well and does not train caregivers well. Our state needs to do a much better job of supporting families in terms of caregiving hours through DDA so that families of all backgrounds can access respite care. Second, there needs to be expansion of parent support programs funded by the state. It would be my sincere hope that our Washington State Government would fund parent support organizations so that these groups can continue to uplift families as they learn to navigate the healthcare system for their children. State investment into these organizations will prove critical for their expansion, quality, and accessibility to all. Last, it is my strong belief that our Washington State Government needs to change their approach to supporting individuals with disabilities; as of now, supporting adults with disabilities holds greater priority to the state as compared to supporting children with disabilities and their families. In no way do I mean to suggest withdrawing support for adults with disabilities, but the support from the state to families with children with disabilities needs to match that of adults with disabilities. Beyond the fact that parents should just get to be parents for their children, rather than hold a dual burden of navigators, it is actually likely going to prove cost effective to invest in these families while children are young:

> “Way back when my son was younger, I was at a Chamber of Commerce meeting, which the county executive was there, and he said, and mind you this was a few decades ago, that ‘for every dollar that they spent for Early Intervention Services, they saved $11.00 later for having to put a kid into Juvi or other types of state systems that these kids shouldn’t end up in. The system really needs to look at this as, if we invest when it’s cheap down here, it is going to pay off down the road.”

Overall, the state of Washington needs to do a better job of supporting families with children with developmental disabilities, because if parents are able to support themselves and their children early on, these children are going to reach their full potential as adults. It is incredibly important that we advocate for the ability of parents to just be parents, and that we speak up for these Washingtonian families who deserve better.

Last, as a call to action for all readers, despite their prior relationships to these issues, I want to speak on the importance of recognizing that outsiders will never fully understand what these parents go through for their children with developmental differences. What is most important is that we encourage the state, the healthcare system and the disability parent community to provide parents with the tools that they need to become empowered advocates for their children. I am going to end by sharing the voice of a disability parent and parent support group leader that was interviewed, as she finished our conversation with this statement as the last thing that I should be aware of in terms of this research:

> "Other than that parents love their children, we know that, the one universal truth that I have found from all parents with kids with disabilities is that without exception, every single one of them thinks they're not doing enough. Every single one. Even the ones who are doing INSANE amounts for their kid, have a list of things they think they should be doing that they are not. And I feel like that would be really helpful for medical

> professionals and everyone else to understand. Helping parents navigate what they need to be doing and what they don't need to be doing is really important. Helping them gain the knowledge to make those decisions is really important. Because that's a lot of pressure, that means every parent is walking around feeling like they're failing their kid."

Conclusion

The utmost goal of this research is to improve the lives of individuals with developmental disabilities. By bridging the gap between healthcare providers and disability parents in understanding how to navigate the health system will in turn optimize the possibility for success for children with developmental disabilities, ensuring that they receive proper services early on in their lives and receive the necessary support to thrive. This research serves to provide a better understanding of what disability parents in Washington State need in order to do what is best for their children, and operates out of a social model of disability to emphasize the need for greater social support for these families. By studying the reliance on community in healthcare navigation, this research will hopefully inspire further studies that aim to address how communities may work in greater partnership with the healthcare system to ensure optimal health outcomes for various other marginalized groups. Overall, this research is dedicated to families who have children with developmental disabilities, who are forced to navigate an endlessly complex health system for their children, and who will receive the benefits of this work if the disability parent community and healthcare community can collaborate with greater efficacy to support them post-diagnosis.

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