

Discovering SSI Benefits, Social Services and Support for Children with Disabilities:

An Action Research Approach

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### **Abstract**

This study examines how parents of children with autism spectrum disorder (ASD), a developmental disability, find federal programs, social services, and support. Parents face numerous challenges in navigating complex systems to improve the quality of life for a child. Using a community-based participatory action research approach, this study examines parents' experiences in learning about programs and services, including the Social Security Administration's Supplemental Security Income Program. Parents recruited in the study participated in an initial meeting, interview, digital storytelling workshops, and a film screening. Our research team conducted constructivist grounded theory (CGT) initial coding and focused coding, developed concept maps, and engaged in memo-writing to discover insights and categories to support findings through the process.

*Keywords:* Social Security Administration, disabilities, autism, parents, action research, digital storytelling

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## **Discovering SSI Benefits, Social Services and Support for Children with Disabilities: An Action Research Approach**

### **1) Introduction**

For many parents of children with disabilities, gaining access to federal programs, social services and support can be life changing. The purpose of this study is to examine how parents of children with disabilities, specifically with autism spectrum disorder (ASD), find federal programs, social services, and support in the community. Using a community-based participatory action research approach, we analyzed the experiences of parents by fostering conversations with a community of parents and applying action research-based strategies to learn about their experiences and possible pathways to improved health and well-being outcomes. By using digital storytelling as a qualitative research method, we also sought to learn how the storytelling process can assist parents in sharing and leveraging their stories to improve the health and wellbeing of their children. The findings highlight opportunities and challenges that parents face.

In addition to ARDRAW support, I was granted the support of an action research working group in the Graduate Studies Program at the University of the Incarnate Word (UIW), from the Robert Wood Johnson Foundation-funded Action Research for Community Health and Wellbeing (AR4CHW) program, which is co-administered by Dr. Alfredo Ortiz Aragón, an action-researcher and designer/facilitator of organizational change processes. This working group consisted of a group of PhD students with a common interest in learning about community-based participatory action research approaches to advance community health and well-being in San Antonio, Texas. I conducted bi-weekly team meetings to focus on ARDRAW research initiatives with this working group. Contributions of team members with activities and data analysis are listed in the acknowledgements section of this report.

#### ***Origin of Research Study***

This research study originated from an action research collaboration led by Ortiz Aragón that was posing the question, *“What challenges are people facing in the community in regard to their health and wellbeing?”* Referring to my personal journey as a parent of a child with developmental disabilities, I shared some of the challenges that I faced in the community attempting to gain access to services. Based on these initial conversations, our inquiry grew into the broader inquiry to investigate and address issues faced by other parents of children, specifically with autism spectrum disorder.

The research is significant to me as someone who has received SSI benefits through the Compassionate Allowances Program, due to having a child born at 24 weeks and weighing 1 lb., 6 oz. We faced many challenges due to prematurity and other medical diagnoses, but with the assistance of a caseworker, I gained access to federal, state, and local services and programs. Once I left the hospital, however, I was on my own in trying to navigate a complex healthcare and education system.

As a member of an online support group and through conversations with other parents, I soon began to realize that I was not alone in this journey and that many parents of children with disabilities continue to look for assistance daily. For example, in one online support group created for parents of children with disabilities in San Antonio, members are actively seeking

answers to questions and requesting support regarding employment, include finding specialized daycare and educational resources, respite care services, and work from home opportunities. Current health and education systems remain woefully unaware and unresponsive to the high touch needs of children with diverse diagnoses. I began to understand that further investigation and lifelong planning are important factors of the process.

Fortunately, after ten years my child is thriving, in large part due to rehabilitation efforts put in place which allowed me to return to work. SSI benefits were important at a key moment in that it helped me with benefits to support my child. Importantly, my child is also thriving because of the relentless and very difficult journey and steep learning curve I faced in doggedly pursuing services for my son when medical health professionals had no answers, when benefits ran out, or when insurance was not helpful with finding funding or support mechanisms. I do not want other parents to have to go through the same processes, when much could be improved by sharing learning that we accumulated by going through the process with important, yet inadequate support. Understanding the experiences of parents of children with disabilities can help paint a fuller picture of the challenges and opportunities faced in their everyday lives, and how they might be overcome.

### ***SSI and Rising Concerns***

Between 2009 to 2017, one out of six children in the U.S. was diagnosed with developmental disability, a significant increase from previous years (Zablotsky et al., 2019). Furthermore, 1.1 million children in the U.S. receive Supplemental Security Income (SSI) benefits from the Social Security Administration (Social Security Administration, 2019). Families with children that qualify for SSI services live either below or near the federal poverty standard (SSA, 2020). With the rapid growth of children with disabilities, additional research can assist the understanding of characteristics, risk factors, and accessibility of services and interventions to improve the quality of life for a child (Zablotsky et al., 2019).

For a child to gain access to medical and therapeutic services, families must be aware of service options that are available (Marshall, 2015). Parents of children with disabilities require additional assistance when applying for funding and accessing information for their families' health and wellbeing (Davis et al., 2016). The limitations and delay of care and other barriers reported by families offer insights into the systemic complexities that families face to access services (Huang, Kogan, Yu, & Strickland, 2005). Furthermore, a lack of coordination and communication between service providers and agencies creates additional barriers that can affect the partnership between families and providers (Murphy & Carbone, 2011). Understanding how families want to be informed and having accessible information is important, yet rarely considered in depth (Mitchell & Sloper, 2002).

### ***Focusing on Autism Spectrum Disorder***

Autism spectrum disorder (ASD) affects 1 in 54 children in the U.S. and, according to the Autism and Developmental Disabilities Monitoring Network, is the fastest-growing developmental disorder (Centers for Disease Control and Prevention, 2021). Parents must make difficult decisions around intervention approaches to access services that impact their children's lives and would benefit from professional support at each stage of the process (Edwards et al., 2018). With the high cost of specialized services, many parents are placed at financial risk by the

burden of healthcare expenses (Stone et al., 2021). The amount of time required for treatment can outweigh the cost of services that a parent can afford. For example, in my experience, if a parent needs rehabilitation services several days a week and does not have the medical insurance to cover the cost, the expenses can start adding up, placing a major strain on other areas of family life. Parents supporting children with autism can play dual roles with responsibilities of being both therapist and parent while caring for other siblings, which can cause complex family dynamics (Boshoff et al., 2018).

Shepherd et al. (2018) suggest that parent-professional conversations are crucial to supporting parents through the decision-making processes. An example of a parent-professional conversation would be a speech therapist and a parent targeting communication difficulty together to discuss treatment intervention approaches. Professionals failing to listen to parent knowledge—for example, parents explaining behavioral issues in the home—can lead to inaccurate diagnosis and ineffective interventions. Parents can benefit from connecting with other parents experiencing similar challenges to advocate, access support, and maintain their well-being (Rabba et al., 2020). This includes parents learning about services through word-of-mouth by friends, family, and others in the community. It is important for researchers to analyze and develop long-term, patient-centric, integrated frameworks and practices to alleviate parents' burden in caring for children with ASD (Helkkula, 2020). In this study, we found multiple barriers that parents face in accessing services and hope to better understand how we can improve those pathways (see findings).

### ***Community-based Participatory Action Research***

Community based participatory research looks at the concept of health from a multidimensional perspective in addressing public health issues in the community (Wallerstein et al., 2018). Action research—another participatory research approach—focuses on local-level problems with the anticipation to find accessible solutions to issues (Mertler, 2019). Action research is a collaborative, democratic process with a participatory orientation, where decision making processes through action and reflection, theory, and practice, assist the discovery of practical solutions to issues (Coghlan, 2019). Action research uses participatory and reflective processes to explore real-world situations that impact the lives of people and their wellbeing (Stringer & Ortiz Aragón, 2021). One of the key principles of participatory research is the open sharing of knowledge by experience owners to inform and help foster social change initiatives and to address challenges identified in the sharing process (Abma et al., 2018). The knowledge gained through participation can change the processes that affect those closest to the issues. For example, bringing parents, healthcare professionals, educators, and social workers together to discuss barriers for children with autism spectrum disorder can put a spotlight on urgent issues needing to be addressed in the community (that no one of these actors can do alone), while opening unique viewpoints from each of the actors involved, each from their respective roles. Knowledge from lived experience from the autism community needs to be heard by public health and other stakeholders and taken seriously at all levels of the research process (Fletcher-Watson et al., 2019).

Action researchers advocate for participation for ethical, practical, and strategic reasons (Ortiz Aragón & Hoetmer, 2020). Ethical, because people have a right to participate in decisions that affect their lives, practical, because people will not buy in over time if they are not respected and included, and strategic, because people's direct experience is needed to accurately

understand their needs (ibid). Abma et al. (2018) explains that action research challenged the notion of research as a static form of inquiry, arguing that “acting” was the basis of learning and knowing’ as a form of inquiry. By engaging with community members with firsthand experience, we can advance our knowledge which can lead to improved outcomes.

### ***Research Questions***

This study explored the following questions:

<b>Questions</b>	<b>Rationale</b>
1) How do parents with disabled children hear about Social Security disability programs, social services, and support through a complex health care system?	To get a better idea how parents of children with disabilities perceive and utilize federal programs, social services, and support.
2) What barriers do parents face in accessing programs, services, and support?	To understand the barriers to care and unmet needs faced by parents in the local community. I am also interested in barriers related to employment opportunities and childcare.
3) Are service providers and agencies offering relevant and accessible information to parents when they need it and what are the information delivery methods?	To understand the satisfaction of information delivery methods used by healthcare professionals and agencies.
4) What do parents’ experiences tell us about strategies that work and problems in gaining access to these services?	To map and evaluate approaches that trigger parents seeking information to become active and knowledgeable advocates to support others and impact policy change.

## **2) Research Design, Methods and Data Analysis**

Using an emergent community-based participatory action research approach, we are examining parents’ experiences in navigating complex systems to learn about the federal programs, social services, and support for children with ASD. Our methods include interviews, digital storytelling workshops, film screenings and multiple parent engagements. Looking forward we will be using the stories created in phase one (the present report) to move into an action planning and implementation phase two.

We chose digital storytelling with the idea that reflecting on lived experiences and sharing these stories between parents would offer rich data that may not be as accessible through other means (Ortiz Aragón & Giles Macedo, 2015). Gubrium et al. (2016) describe digital storytelling as a process-based methodology which includes a process co-mediated by researchers, workshop facilitators and other group members, that support each participant through the process. This research method holds potential to explain complex stories in an accessible manner and increase participant engagement with the process. Storytelling as a research tool has the potential to capture lived experiences of participants in a highly engaging digital platform (McCall et al., 2019). Studying visual data can open new possibilities to develop grounded theories that construct social problems visually (Charmaz, 2014). Digital storytelling is

a participatory research tool that advances research processes to enable participants to make visible the meanings they attribute to specific events in their lives with others (Stringer & Ortiz Aragón, 2021).

Digital storytelling integrates all three of the cognitive processing systems, visual-object, visual-spatial and verbal, which can facilitate a deeper level of self-expression and understanding within diverse areas of inquiry (Rieger, 2018). A study conducted by Urstad et al. (2018) described how participants of digital storytelling promoted ownership of reflection, which encouraged a deeper understanding of the experience. This method uses technology to build on the experience of storytelling by showing the story through digital media and viewings. Process-wise, StoryCenter explains seven components of a digital story, including that they are self-revelatory, use first-person voice, are experiential, integrate photos, length and design, and intention to create a story (Lambert & Hessler, 2020).

### ***Research Participants, Recruitment, and Sample***

To be part of this study, participants needed to be over 18 years of age and a parent of a child with autism spectrum disorder. To recruit participants, we created a social media post and flyer to share with online parent support groups such as San Antonio Special Needs, San Antonio Autism Group, Autism Society of Texas San Antonio, Autism Society of San Antonio Support Group-under ASCT Chapter, and Foundation School of Autism. The post had information describing the study and an invitation to participate in the study. These groups specialize in supporting parents of children with disabilities and ASD. In addition, an email describing the study was sent to identified organizations to request the distribution and invite parents. Subjects could exclude themselves from participating in the study at any time due to time constraints. In the initial meeting, we met with participants to review the project requirements and provide informed consent information. 12 parents, 11 female and 1 male, all in San Antonio, participated in the study. Participants offered diverse experiences and backgrounds. We conducted initial pre-screening meetings with parents to share information and informed consent.

### ***Measures and Procedures***

#### **Training and Preparation**

In preparation for research activities, our research team met bi-monthly and focused on activity planning. The team also met weekly to discuss our connections with the broader UIW AR4CHW project mentioned earlier. In preparation for this study, I completed a 10-week Digital Storytelling Online Certificate Program through StoryCenter to enhance my digital storytelling facilitation skills through a Facilitator Intensive Master Class. I also conducted a Digital Storytelling “Dress Rehearsal” Pilot Workshop with a group of UIW PhD students with the idea of gaining feedback on writing instructions, video creation and presentation skills to refine research method tools needed for future activities. Lastly, our research team completed data analysis training on Constructivist Grounded Theory approaches for data analysis purposes.

### Planning & Initial Meetings

Parents attended individual “Meet and Greet” sessions with the action research team to gain a better understanding of the project timeline, activities, and requirements. This was a crucial step between parents and our research team to help answer questions and build relationships in the study. We started with an introduction of the research study by providing an overview describing the scope of the project, and of ourselves by engaging in get to know each other activities. We provided an overview of action research and CBPR practices with parents to provide background knowledge. We reviewed informed consent information before moving forward.

### Pre-Interviews

Our research team conducted 12 individual interviews with parents. We provided an overview to parents, followed by requesting consent to start recording. Each interview began with an introduction where each participant could introduce themselves with a check-in, followed by open-ended research questions, see **Table 1**, starting with the earliest indication of support needed. We asked about key moments, pathways to services, accessible information, challenges, and opportunities. All videos were recorded using Zoom web conferencing and transcribed verbatim.

*Table 1: Pre-interview questions for twelve participants*

<b>Pre-Interview Questions</b>
a) Can you share more about your experience of being a parent and how you first learned your child needed additional support?
b) How have you been able to find programs, social services, or support for your child?
c) How has a specific organization or person helped you find relevant information that pertains to your child?
d) Describe a time where you experienced a barrier or challenge in gaining access to a program, service, or support for your child?
e) Describe a time where you experienced an opportunity in gaining access to a program, service, or support for your child?
f) What resources would you love to have to assist your child and what does that experience look like?
g) Have you received programs, services, or support outside of the state of Texas? If so, where and can you describe your experience?
h) How are you informed about state laws or policies that may pertain to children with ASD?
i) What would you like to learn more about to support your child by gaining additional knowledge through education or training?
j) What do you believe defines success when supporting your child’s needs?
k) What advice would you give to new parents starting on their journey to better support their child in gaining access to services?

### Digital Storytelling Workshop: Overview and Writing

We offered a total of four digital storytelling sessions based on parents' available schedules. In the first digital storytelling session (overview and writing), we presented an overview of StoryCenter's digital storytelling seven steps to parents to help them think about writing a first-person narrative. The steps include: 1) owning your insights, 2) owning your emotions, 3) finding the moment, 4) seeing your story, 5) hearing your story, 6) assembling your story, and 7) sharing your story. As the facilitator of this workshop, I offered questions as writing prompts for parents to think about key moments in gaining access to programs, services, or support.

We then facilitated a writing activity with a designated time for parents to start writing their story. Afterwards, we created a "story circle" for parents to share stories and offer discussion. A story circle is a space created by a facilitator for participants to share what has been written in a previous writing workshop with others. In preparation for sharing, we asked parents throughout the workshop whether they would like to share their stories and reminded them that they can stop at any time. We offered additional time and instructions before proceeding to the next activity, which was the video creation process.

### Digital Storytelling Workshop: Video Creation

The second digital storytelling session focused on video creation, where parents learned how to assemble stories in a video format. We offered a total of three digital storytelling sessions for parents based on available schedules. Participants brought a writing sample of their story to the virtual workshop to begin assembling a video. We provided an overview of the video editing process for writing, audio recordings, images, video clips, sounds, and transitions. We granted parents access to WeVideo, a video editing software, to begin narrating their stories. Before ending the workshop, we exported the videos for group discussions to take place. We offered additional time for parents to assemble their stories and seek assistance. Parents completed a total of seven videos throughout the process, described in more detail in **Table 2**.

*Table 2: Description of digital stories*

<b>Parents</b>	<b>Video title</b>	<b>Focus of the video</b>
Video A	Fighting for Respite Care Services	A parent's struggle in a long process to seek access to respite care services.
Video B	Paying for High Cost of Services	A parent's challenge to pay for the high cost of therapy services.
Video C	Accessing Support in a School Setting	A parent's experience in challenging the school system to seek access to services.
Video D	How Experience Leads to Advocacy	A parent's struggle with accessing the right service in school which led to her becoming an advocate.
Video E	Hearing my Son's First Words	A parent's concern for her child's speech delay and the joy she felt hearing his first words.
Video F	Having a Choice in a Child's Care	A parent's journey in seeking support for her child and feeling empowered by meeting other parents.
Video G	Finding Inclusive Activities in the Community	A parent's excitement in watching his child develop and grow through an inclusive sports organization.

### Parent Film Screening

We offered two film screenings for parents to attend. In each screening, we celebrated parents and watched all the stories created in the digital storytelling workshops. We also shared information by presenting “navigating the system” and “pathways to services” from data collected. The idea was to show an illustrated map of a city where the road starts in one place and separates into different pathways before coming together at the opposite end. For example, two parents may need respite care, yet based on medical coverage, one may find a shorter road to receive services and the other may be in a roundabout intersection waiting for services. Next, we showed a flow chart constructed by data collected in interviews describing an entry point in navigating services before encountering steps of approval, denial, and waitlist to understand the challenges that parents face. Afterward, participants watched each video and reflect on their journey. Parents discussed what they learned and offered insights moving forward.

### *Analytic Plan (Data Collection)*

As noted earlier, our research team used Zoom web conferencing to audio-record videos for interviews, digital storytelling workshops and the film screening, all of which we transcribed verbatim. We followed a qualitative research data analysis approach from the methodology Constructivist Grounded Theory (CGT) to discover insights that supported our findings. Using this approach, we employed initial coding practices through line-by-line coding, focus codes, concept maps, and memo-writing. Line-by-line coding allows researchers to gain detailed data about fundamental empirical problems and processes (Charmaz, 2014). In Fall 2020 our research team worked collaboratively to find patterns in the data from interviews to support analysis. We conducted coding individually and came together using a Padlet board to share and identify partial categories of challenges expressed by parents. Through this approach, we learned how observations can reveal everyday life, compelling and consequential scenes, and actions (as shown in our findings).

We presented the information to parents for discussion in the parent film screenings, where we collected additional data for future analysis. In the Spring of 2021, researchers participated in a second round of data analysis to re-evaluate patterns, using the same process and compare previous data to develop insights of parent interviews, digital storytelling workshops and film screenings. We discussed findings in the research to develop categories for the results and findings section.

## **3) Findings**

Findings from this study are relevant to the methods we used in interviews, digital storytelling workshops and parent film screenings. Our approach in developing the findings derived from Constructivist Grounded Theory approaches to connecting patterns and organizing categories with sample quotes from data collected. Participant names in the statements below have been changed to protect their identity.

The findings are broken down into six themes:

### ***Health Care: Retelling the Story, Seeking a Diagnosis to Access Services***

There are often long waitlists and cumbersome intake requirements for children diagnosed with ASD. Obtaining a diagnosis is vital to early childhood intervention approaches. Locating information and resources is directly tied to how early a diagnosis is made. If a child is diagnosed early, there is greater access to hearing about resources.

*"I want to say diagnose better. But this one thing that I see in common it's like, is getting the right people in the room to make sure that the best outcome is in the best interest of the child." – Parent 7*

Yet in order to obtain an ASD diagnosis, parents had to continuously retell their stories to healthcare providers and other specialists. In some cases, parents needed to be relentless in becoming experts in their child's medical care to obtain a diagnosis.

*"Well, at that time, I took him to the local pediatrician. They checked his hearing, and everything checked out, okay. Because he was meeting his milestones other than the not turning to his name. No one really took me seriously. So, I've been to several doctors, and at that time, ... he'll grow out of it, that type of thing. So, it was not until 2011 the developmental pediatrician, which we waited nine months to see, diagnosed him with autism." – Parent 6*

*"I knew that I needed that diagnosis in order to get him services. Like, I needed that diagnosis in order to open up doors, to get him, to get him what he needed. and I also knew that with that diagnosis, if that's what we we're dealing with, with being properly diagnosed. I knew that we were going to need it for school, and I also knew that I was going to need it for Sam to get on certain, like Medicaid waiver programs. I think the big one for us was, I felt like we really needed it because I was trying to work in a critical window. You know, I knew that just from trainings that I've been through, I knew that, you know, we had certain windows or opportunities in the brain open during certain times and they are all under three years and I wanted him to get the services he needed to give him the best start." -Parent 12*

Some doctors were unable to offer a diagnosis or referral, believing the child would eventually "catch up", yet parents continued to feel something was not quite right. In the statement below, one parent describes her feeling of relief when hearing about an organization that offers assessments from children.

*"My doctor didn't tell me, you know, all these professionals that you would think would have this information. So, I'm sitting on this chair, and I feel like I couldn't breathe. My shoulders were tight. I was there to pick up my older son and this lady's telling me all this information and all I feel is this release. Like, oh my God, you called Who?"- Parent 4*

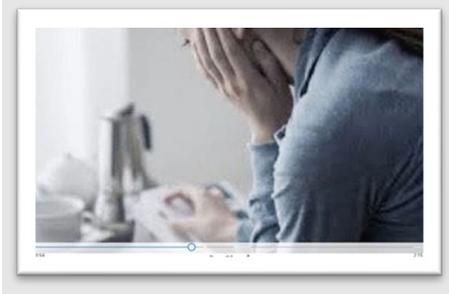


Figure 1, Video A:  
Fighting for Respite Care Services

In this video produced by a parent, she described her experience with a doctor and how he told her to “investigate respite care services”, making it sound simple. Unknowingly, as she started looking for services, she continued to wait months to access them. The journey can be emotionally and physically exhausting for parents, yet they continue to fight for services because they believe their children deserve it.

Accessing an autism diagnosis for a child can turn into a long-complicated process for a parent. Learning how to navigate services is crucial for parents to understand where to seek a diagnosis and who can offer a diagnosis in the community.

### ***Financial: High Cost of Services, Paying for Care***

Access to services can be out of reach for children whose families exceed income level requirements and qualifications. We found that parents perceive qualifying for services by income level a burden to accessing medical and therapy services needed to care for a child. Parents were often told to call their private insurance company, only to find out that services and equipment may not be covered. One parent described it as feeling outed by a caseworker.

*“And she could probably qualify for Social Security with that type of Medicaid, no, she doesn’t qualify, I’ve already applied, you know, and I said, we own a home, we own two vehicles. I mean, but those are things that you need in life, you know, nowadays, you have to have two cars, you know, for us to work, my husband works. He’s always on the road, you know, and stuff, and I need a car for Amy. So unfortunately, that, too, has gone against you, you know, because you have two cars, they think, oh, you have two cars, you can afford these things. But you know what, that’s, that’s a necessity nowadays, you know, and we don’t live lavishly. You know, we have a very humble home, we don’t live beyond our means. But at the same time, we have, we had four kids that we had to raise, you know, not just Amy.” – Parent 9*

Parents explained that the high cost of services was an unfair barrier in gaining access to services, which would result in their children not benefiting from specialized therapy services. In some cases, private insurance would only cover a specific number of hours, even when a therapy company would require additional hours for the child to receive the best results of recommended treatment.

*“They were charging \$50 an hour. And I’m like, I can’t make it. If I was to work every single day, like, I can’t make it. He needs at least three hours every day, you know. So, I would have to have like a really, really, extremely good job like \$100,000 a year or something so that I can make these [payments for] a day alone. And maybe like two or three days out of the week. I think that it’s that or something like that.” – Parent 11*



Figure 2, Video B:  
Paying for High Cost of Services

In this video, the parent tells the story of having to explain the cost for Applied Behavior Analysis (ABA) services and how many children go without it. She describes how the cost for services can add up and parents must pay out of pocket. In some cases, insurance covers less hours required for treatment.

To help cover the cost of services that insurance would not cover, a few parents told us about grants they found through word of mouth from non-profit organizations. They described finding grants as challenging but once a parent was able to receive one it was extremely helpful.

*"They don't care how much money you make, like they just like, they just want, like, a list of all your bills, and you just write them down. Like, you don't need to send proof, like, you just, they just want you to be true and honest about your bills. And then they'll give you a hand. So, no one goes to ABA therapy, free of charge, because our insurance covers the majority of it, and the Masonic group gives us a grant. And this year, he got \$1,800. So, it covers the \$15 a day copay for everyone."- Parent 1*

Paying for services can take a toll on parents financially with the high cost of services. Additional resources such as grants can help to reduce the cost. Yet, many parents are unaware of these services and struggle to obtain important services for their child.

### ***Education: Challenging the Systems, Moving Schools for Support and Services***

Interactions with administrators and teachers in public school districts and systems can represent a significant challenge for parents of children with ASD. Several parents became increasingly frustrated in understanding how a medical diagnosis of ASD would not automatically qualify a child for services and support in the school system.

*"So, that right there, that double testing and more testing, and it's like a whole day, it's just ridiculous to have a three-year-old sit there for two and a half hours to take this test. So, I think the education system, too, was a barrier in that sense, where I'm giving you all the information. These are all his diagnosis. He's speech delay, he needs physical therapy, because he couldn't hold the pencil, right? He would hold it this way. And so, that's occupational therapy. They're already telling you this is what he has, but yet the school wants to say, oh, no, no, we have to diagnose, and we have to test him. And who are you? Who are you all to rechange his diagnosis? Nope, he doesn't need that. I'm like, yes, he does. So, a lot of stuff we had to do at home, and a lot of stuff. I said, okay, that's what it takes to be in the school district. Fine!" – Parent 4*



Figure 3, Video C:  
Accessing Support in a School Setting

In this video a parent tells the story of trying to understand how a school district could deny her son's ASD medical diagnosis. With her education background, she continued to struggle in gaining access to services with the special education department. Despite all her research, constant meetings, and safety concerns, she ended up having to move her child to a local charter school for autistic children.

Many of the parents moved their children across public, private, charter and home school based on challenges in gaining access to services. One parent described moving to a new school, only to find herself in the same situation.

*"And so finally, we moved houses. And we went through like, this is one of the best schools in San Antonio, it's going to be great, you know, he's going to do fine. And it kinda went good. You know, he had some difficulty, but his teacher was very good. And so, we were like, okay, we're gonna do fine, and came first grade. And that's when the real troubles began. That's when you really started to see that the services in support for him were not the right kind of services, and where the schools themselves didn't really have the accommodations needed for him." - Parent 10*

Effective communication is essential between educators and parents working together to address services for a child with ASD. Moving across school districts to access services can be challenging and have a long-lasting effect on a family.

### ***Employment: Changing Careers, Needing Flexibility***

Parents of children with ASD often have medical appointments and weekly therapy appointments to support the healthcare needs of a child. Work accommodations, flexible schedules, and healthcare benefits were perceived by parents as beneficial to a positive work-life balance. One parent shared with us how she takes her child to work with the support of her supervisor, yet she has also been waiting for months to access respite care services.

*"And I was having to take Amy with me to work. And so, I was trying to find, you know, like a caregiver program where someone could come to my home, but a family member or someone that I could trust, and they would also, you know, get paid at the same time where they could be in my home because of COVID. Yeah, but here in my home . . . I work in an office setting . . . and so thankfully, he's very understanding. I've been there since she was a year old. And I work part-time because of the Amy. Yeah, I'm able to get off on time, get her to therapy, take her out of school, if she's had, you know, meltdowns at school. I'm able to just get up and go. So, I'm very grateful that he was able to let me take her to work, and I still take her to work with me."-Parent 9*

Yet other parents left jobs, downsized to a part-time job, gave up potential career paths or worked weekend shifts to care for their child with ASD. Accessing respite care programs, finding specialized childcare with ASD training, and safety concerns in a school setting all contributed to their employment challenges.

*“I would get called to pick him up from school, at least minimum once a week. It became so it started to affect my job. So, I had to quit. And, and, and it’s just, it’s terrible. Horrible. I had him in after school care. And they could not take care of him there either. I kept getting called literally every single day. They cannot take care of him. I had a teacher when my son was in third grade who texted me and said, she said, through text, I don’t know what to do with your son anymore, but I have X amount of other students that are suffering because of him.” – Parent 12*

Parents of children with ASD in our study often consider changing career pathways to manage the care of a child’s healthcare needs.

### ***Information: Searching for Answers, Facing Information Overload***

Parents expressed information overload when meeting with caseworkers—describing feelings of being emotionally overwhelmed when signing up for services with huge binders. Parents suggested that service providers need to offer easy to understand and accessible information.

*“The caseworker just signed me up for all kinds of stuff. And she’s like, I’m signing you up for this, this, and this. At that time, it was like a slap in the face. All this information. I’m doing this business, and I’m like, okay, whatever, like, okay, you know, I didn’t have a pen or pencil, or paper, at the time. So, I didn’t write anything down. I was like, okay, thank you. I just kept in contact with them since then.” -Parent 1*

Parents also shared positive experiences searching for information online through Google searches and asking questions in online support groups. They turn to free activities, specialized services, and training resources for support.

*“I’m like a Google champion. Like, from when I was in college, like, for my bachelor’s degree, Google was still pretty new. So, you had to be like, you had to know the right words to type into the search bar. So, I’ll just do like browse, just like, special needs pediatrician in San Antonio or whatever.” – Parent 5*

Offering accessible information to parents is crucial to helping them find resources in healthcare and education settings.

### ***Wellbeing: Being Emotionally Invested, Taking Time for Self***

Parents expressed frustration with navigating complex systems to access services, feeling isolated from the lack of understanding, yet being emotionally invested in supporting their children. One parent shared her struggles with us by comparing diagnoses.

*“You know, I grew up neurotypical, I didn't grow up with anybody with any kind of disabilities. I don't know what steps I need to take, and like for you six years, you think you're just for six years. Hmm. And then you get denied. Like, the problem should be why am I on the list for six years? Oh, imagine if someone who was diabetic was like, well, you're diagnosed diabetic, but we can't get you insulin it could possibly take six years.”*  
- Parent 2

We learned about strategies parents use to manage self-care. This includes spending time with family and friends, reading a book, watching a movie, and learning new things.

*“So, just as you would take care of your kid, you need self-care for yourself. I think early on with my son, I forgot that. And it did cause some tensions because you thought, well, they can't watch my kid because they don't know or in my much for them, or they might not know what he wants, because he can't say anything. And they don't know. It's getting adjusted to what you're comfortable with, but also getting adjusted to what you're not comfortable with. If you don't have a healthy state of mind, for yourself, how can you have a healthy state of mind for your kid, um, like I said, you know, even if it's something small...”* -Parent 2

Parents expressed being emotionally invested in their child's care. They found various self-care activities to support their wellbeing.

#### 4) Discussion

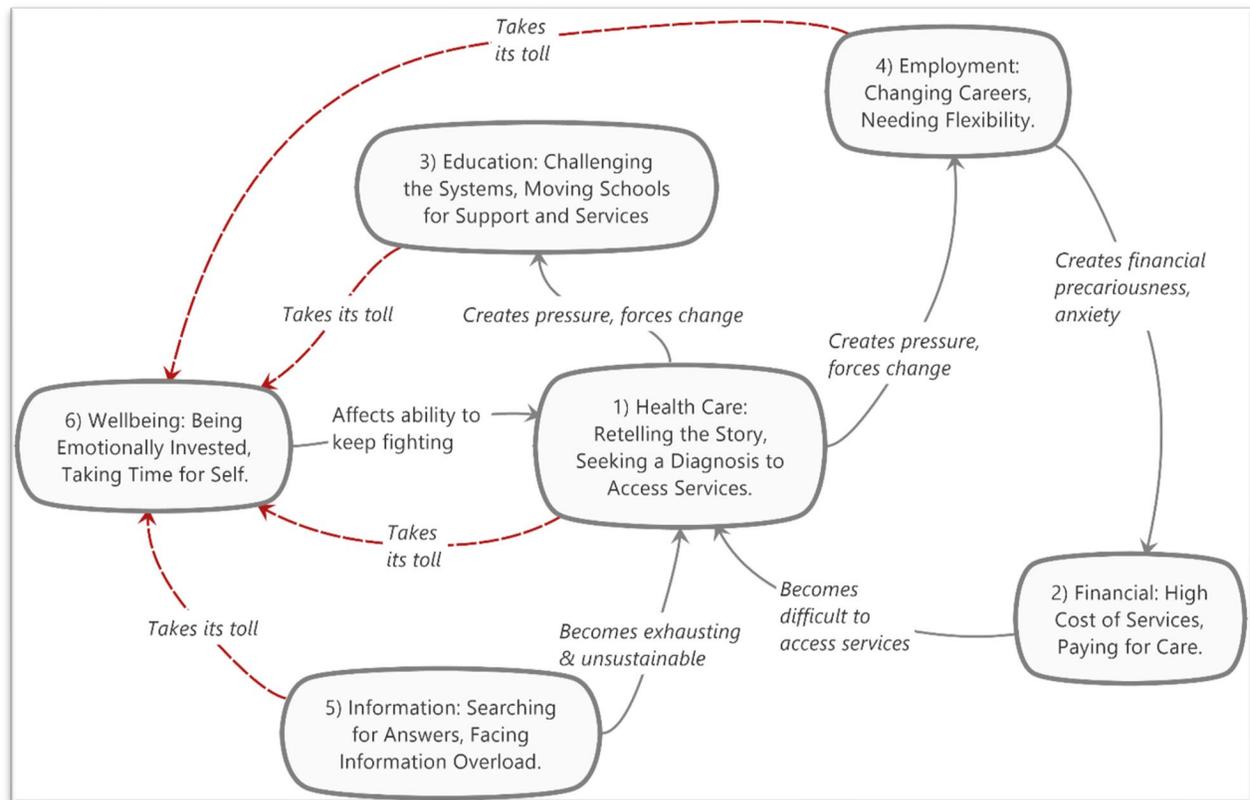
##### *A conceptual model from parents' experiences*

A parents' journey to find federal programs, social services, and support often begins through an observation made by a parent or other person in close contact of the child, which leads to them contacting a healthcare provider or organization in the community for assistance. Once an appointment is setup, a referral can be made for an assessment. If the criteria are met, a diagnosis is provided for the child. In this study we learned that this could be a constant process that can take several weeks or months. In some cases, parents had to make multiple appointments with specialists to plead their case. An eventual diagnosis opens the doors to apply for programs, including the Social Security Administration's SSI program. Depending on the program, income level requirements play a factor in parents from moving forward in the process. Parents that meet eligible requirements can be placed on a waitlist for an extended amount of time. Through this process, we learned that new parents of children with ASD can learn about services through health care providers, rehabilitation specialists, social workers, educators, google search and word-of mouth by other parents.

In **Figure 4**, we present an overall model that tells the story of how the six major areas of findings come together to create a vicious cycle of parental experience in accessing services. I will briefly describe the model starting with parents (1) addressing healthcare needs by constantly retelling the story to seek a diagnosis to access services (2) managing the high cost of

paying for services (3) challenging the education system, moving schools and seeking access to support and services (4) changing careers and needing flexibility, (5) seeking information, searching for answers, facing information overload, and (6) managing their wellbeing, being emotionally invested in their child's care while needing time for self-care. Throughout this cycle, pressure is created which forces change, becoming exhausting and unsustainable, difficult to access services, while taking a toll on the parental experience through the cycle.

Figure 4: An overall model of parental experience in accessing services



### ***How digital storytelling helps parents reveal and grapple with their experience***

Parents of children with autism come from different walks of life, yet there are similar patterns that can be found in accessing services. Some parents may have a difficult time talking about a diagnosis, expressing concerns of being labeled and discriminated against. As we have seen, parental experience can be life-long challenging, all-encompassing, exhausting and continually changing (Boshoff, 2016). Additional support is needed for parents to initiate these discussions (Crane, 2019). Parents can use digital storytelling to offer a glimpse into their experiences by using video to assemble text, pictures, video clips, and music in ways which can stimulate the mind (Beck, 2020). Furthermore, digital media can enhance the storytelling experience by enabling different ways of thinking and means of expressing knowledge (Johnson & Kendrick, 2017).

Through the digital storytelling process, we found that parents underwent transformative experiences by reflecting on, writing, sharing, and producing their story. In story circles, they shared pivotal moments with one another and heard each other's stories. In Figure 5 for example, a parent assembled a story of a challenging situation that led her on a path to advocate for others. Another parent shared how after hearing everyone's story, she realized she was not alone. She wanted to figure out more ways to access resources and help the community. This was a pivotal moment in her transformation to emerge as a future advocate. Parents can use these experiences to continue to persevere with a desire to champion their child's success. There can of course be similarities in stories shared by parents as well. By telling universal stories, we believe it can offer an opportunity to bridge the gap of barriers that impact people's lives.



Figure 5, Video D:  
How Experience Leads to Advocacy

In this video a parent describes how her child with ASD faced numerous challenges in a public-school setting. Administrators and educators presented compliance training which she described as seclusion from others. This experience drastically changed her life to pursue an advocacy role for more teacher training to help her son and other students to become more successful in the classroom.

There are still so many untold stories needing to be valued and heard. We believe that when parents find their voice it is an important part of the transformation process to advocacy. Hearing the collective voice of parents, educators and specialists are important to ensure a child's needs are being met and support is put in place for educational success (Saggers, 2019).

In the parent film screenings, participants expressed the desire to find a better way to locate services. We believe that providing accessible information to parents is critical through effective communications that digital storytelling processes can offer. Parents of younger children that participated in the study learned from parents with older children based on challenges faced over the years. Studies are needed to identify early processes viewed by parents and professionals to help shape future services (Crais, 2020). Service providers and those that support caregivers of children with autism can identify pathways for appropriate intervention at relevant stages (Broady, 2017). Meaningful participation and conversations about ASD through digital storytelling action research processes with parents and partners in the community can offer a facilitative environment, answer relevant questions, and implement structure (Fletcher-Watson, 2019).



Figure 6, Video E:  
Hearing my Son's First Words

In this video a parent of a child with ASD shares a pivotal moment when she hears her son's first words. She felt happy because she was unsure if her son would ever talk. In that moment, she realized that she could never give up on him. She decided to get as many trainings as possible to help her son communicate with herself and others.

In phase two of this study, we hope to continue conversations in the community with educators, healthcare providers, social workers, and representatives, which can offer new lenses to understanding and overcoming service provision challenges. Funding at the state level and waitlists for services continue to dominate conversations. Inviting stakeholders and those that serve this community can offer new insights into the practice, policy and processes that may be barriers to parents in accessing services. Through this process, we learned that parents could tell powerful stories based on their lived experiences that may have the seeds for transforming those experiences in the future.

### ***Limitations***

Parents face many challenges in managing their child's health care and education, and their own careers, and family life. Even though we did a lot to accommodate their schedules to attend online activities, it was not always possible. This may have impacted recruitment and involvement, and the number of participants that may have wanted to participate in the study. In addition, our research was conducted during the COVID-19 pandemic. All meetings and events took place online through Zoom web conferencing. Participants were required to have access to a computer and microphone at home for video editing and connection to the internet. If a participant did not have these resources, it limited their participation and number of participants in this study. Lastly, we realize that elements of this study may be unique to the San Antonio area and may be different in other geographic locations based on income requirements, state policies and funding opportunities.

### ***Connections to Social Security Administration***

By engaging with parents in the first phase of the research study through an emergent process, we listened to a number of challenges that parents expressed in accessing services. The purpose was to better understand how parents perceive these experiences and the barriers they face when services go unmet. During the interview process, parents shared their stories of applying for Social Security Administration benefits and described how information was provided through word-of-mouth by caseworkers, friends, and family. For example, one parent described not knowing who to contact about accessing Social Security Administration benefits and not knowing where to begin to sign up for services. In another example, a parent described hearing about Social Security benefits from a friend. Yet, the parent was unsure of the medical and income level requirements which prevented the enrollment of services. Providing accurate and up-to-date information is pivotal to helping parents make better informed decisions. As we

make these connections with parents in the first phase of the research study, we want to have more meaningful conversations connecting to the importance of SSA benefits in the second phase of the study. Through our initial conversation with parents, we now have a better understanding of the process for phase two of the research study and what questions to ask as we continue the conversations.

## **5) Summary and Conclusion**

We believe that the findings in this study and the stories told can serve as resources to serve and educate parents, service providers and others to address issues with service provision in their communities. Early diagnosis for children with autism was expressed among parents as crucial to gaining early intervention services to enhance a child's health outcomes. Through the obstacles, parents have a resilience by continuing to ask questions, moving through the process, and seeking support. Digital storytelling can help both get the story out and help parents learn from each other in the process.

The experiences parents face can be challenging, yet there are a number of opportunities to make improvements. Having accessible and up-to-date information is vital for parents in accessing services and sharing these resources. Having the community come together—including through digital storytelling processes—to discover solutions to barriers through conversations can help achieve social change in vulnerable populations. Understanding the daily struggles of parents can expose gaps of services and risk factors. Digital storytelling can offer insights into parents' lived experiences and personal reflections. In addition, education and training through community classes can teach parents new skills needed to navigate complex systems.

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