Discovering Supplemental Security Income Benefits, Social Services and Support for Children with Autism: Phase II Planning and Taking Action

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Abstract

Parents of children with autism spectrum disorder face numerous challenges navigating a complex healthcare and education system. Using a community-based participatory action research approach, researchers and participants implemented action planning cycles using stories for action-oriented advocacy opportunities within the community. Through this study, parents participated in planning meetings, building relationships with community partners, and training workshops focusing on changing narratives using story-based strategies, leading to an activity called “Rewriting the Script” with parents and pre-health professional students. We hope to learn how participant experiences can serve as a catalyst for dialogue in the community to support policy and social change. Findings are based on the participatory actions taken, research activities, data collection, and analysis.

Keywords: Supplemental Security Income, disabled children, parents, action research, digital storytelling

Table of Contents

1) Introduction

Parents of children with autism spectrum disorder (ASD) face multiple challenges in gaining access to social services and support to improve the quality of life of their children. According to estimates from the Autism and Developmental Disabilities Monitoring Network by the Centers for Disease Control and Prevention, about one in 44 children in the U.S. has been identified with ASD (CDC, 2021). Texas has the lowest prevalence rate for ASD diagnosis when looking at state-by-state comparisons (Xu et al., 2019). The growing number of children with ASD in Texas has parents desperately seeking access to services and federal programs that can outweigh current services offered in the community, such as diagnostics services, therapy services, and specialists' care. In San Antonio, Texas, and surrounding areas, 1 in 79 people currently has ASD (Kronkosky Charitable Foundation, 2016). Over 30,000 people live with ASD, with a projected increase of 2,500 people every five years due to population growth (Autism Prevalence Assessment San Antonio CBSA, 2016). According to the Texas Autism Council (2019), the increasing number of people with ASD has put a strain on state resources which has increased the long waitlist for services.

The purpose of this overall study through two phases is to: a) identify opportunities and challenges that parents of children with disabilities face through their lived experiences; and b) to help parents find federal program benefits, social services, and support using participatory action research approaches. Phase 1 explored how parents of children with ASD gained access to services and support. Phase II—"Planning and Taking Action"—looked at how access might be improved through participatory action research processes in which parents actively participate and take action in their own change processes. Phase II seeks specific opportunities to expand the research, learning, and access to services through direct action, and continued expansion of the previously initiated conversations and research. We now explain each phase of the research.

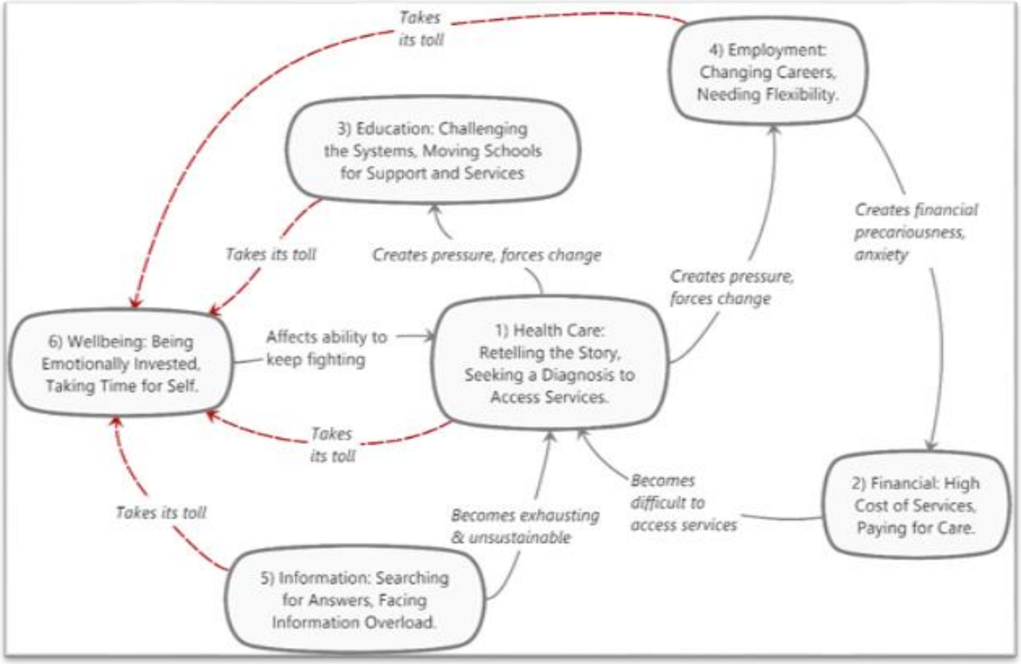
Origin of Research Study: Phase I

Phase I of this community-based participatory action research process—"Discovering SSI Benefits, Social Services and Support for Children with Disabilities: An Action Research Approach"—went from July 2020 to June 2021. In phase 1, parents were invited to create digital stories of their lived experiences in accessing services and support for their children with ASD. In addition to ARDRAW support, I was offered 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 Ph.D. 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. Support included the design, testing, and evaluation of action research approaches that increase participation and strengthen existing community health and wellbeing efforts in targeted groups.

In phase 1, our research team met with parents of children with autism and other community knowledge holders, including special education teachers and autism professionals, to gain background knowledge of ASD. We then recruited 12 parents of children with ASD through social media posts, online support groups, and organizations that offer autism support and services in San Antonio, Texas. Afterward, we built relationships with parents by conducting planning and initial interviews and facilitating digital storytelling workshops, which included writing stories and video creation. We then convened a parent film screening and carried out additional data analysis processes with the research team. I personally completed two online digital storytelling training series for professional development to help me effectively prepare and implement each workshop. By using data analysis approaches from Constructivist Grounded Theory, we were able to identify patterns and derive meanings from the data.

We created a conceptual model that highlighted six major areas of findings showing a vicious cycle of parental experience in accessing services. The model in **Figure 1** shows 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, but sometimes feeling compelled to move schools and even having to (4) change careers to achieve needed flexibility. The parents never rest as they find themselves constantly (5) seeking information in their search for answers, yet facing information overload, which leads to decreased well-being (6) because of not being able to attend to self-care that is needed to keep up this level of emotional investment in their child's care. Throughout this cycle, pressure is created which forces change, becoming exhausting and unsustainable, remaining difficult to access services, while taking a toll on the parental experience.

Figure 1: An overall model of parental experience in accessing services



It is important to note that many of these issues were problematic pre-pandemic (our study began just as the pandemic was taking hold). Yet, the pandemic amplified parent voices to bring a greater need to improve the quality of life for a child. We learned that parents of children with ASD underwent transformative experiences by creating digital stories. By transforming into future advocates, they can become champions for their children's success and future healthcare.

Where We Are: Phase II

In Phase II—"Planning and Taking Action"—our small team continued to use a community-based participatory action research approach to implement action planning cycles that helped the parents use their digital stories as a starting point in what would become action-oriented advocacy opportunities within the community. By expanding dialogue between parents, practitioners, and community members, I hoped to learn how existing barriers of parent stories can support advocacy initiatives that lead to developing a framework of action-oriented solutions.

My secondary aim with this approach is to explore how we use knowledge to connect and influence, deepen understanding and expand approaches, and connect the conversations with existing autism services. As is common in action research studies, designing specific tools and methods for inquiry is consistent with emergent research processes. I hope to generate knowledge by sharing stories and creating data visual activities, with targeted key influencers in the community for learning purposes and social change. This next phase of the action research process moves from investigation and understanding to systematic action based on the challenges that have surfaced from previous activities (Stringer & Ortiz Aragón, 2021). The focus of having workshops will be based on what has been learned in Phase I of the research study through data analysis and parent meetings. The objective of the activity focuses on the priority of health care challenges, early intervention, and access to services.

Research Questions

The research study explored the following questions:

Questions	Rationale
Q1) How do we continue exploring barriers that parents face in accessing programs, services, and support?	To understand the barriers that parents have previously shared and explore the connections with unmet needs in the local community.
Q2) How do parents navigate complex healthcare and education systems? What opportunities can we see that we could not before?	To use the previous knowledge gained and dive into deeper questions that parents face when accessing federal programs, social services, and support.
Q3) How can we work with parents, community members, and boundary partners to initiate conversations that explore current gaps and increase existing knowledge among stakeholders?	To understand how we can generate knowledge in a group dynamic with community members.
Q4) How might we support more parents to move into advocacy roles to support their own pursuits for adequate services for their children, and support other parents' ability to learn about the federal programs, social services, and support?	To help parents become active and knowledgeable in discovering and sharing resources.

2) Research Design, Methods, and Data Analysis

Using an emergent community-based participatory model, we invited parents from our previous study and recruited parents with Any Baby Can San Antonio, a local nonprofit that serves families of children with healthcare needs. Our methods included emergent activities through action planning processes such as planning and initial meetings, building relationships with community partners, and training workshops focusing on changing narratives using story-based strategies, leading to an activity called “Rewriting the Script” with parents and pre-health professional students. This included sharing stories, rewriting stories from negative to positive outcomes, parent check-in survey, classroom art gallery walk, parent check-in, community planning event and lastly the creation of an art exhibit.

We worked with parents and boundary partners to actively engage in learning, sharing, and generating information, and participating in activities to advance knowledge collectively. We hoped to share new information that is useful to those serving children with ASD at the local and state level by understanding the experiences of parents as they navigate a complex system to improve programs, services, and support. We want parents to receive the tools needed through learning that takes place within this project to become lifelong learners and to develop plans to support their children in the future with advocacy initiatives.

Research Participants, Recruitment, and Sample

To be part of this study, participants were required to be over 18 years of age and a parent or caretaker of a child with ASD. Subjects could exclude themselves from participating in the study at any time due to time constraints.

We recruited 12 parents of children with ASD through social media posts, online support groups, and organizations that offer autism support and services in San Antonio, Texas. Parents from Phase I were also invited back to participate and new parents were recruited from Any Baby Can San Antonio where a total of six parents all female signed up to participate in Phase II of the research study.
We met with participants to review the project requirements and provide informed consent information. Participants offered diverse experiences and backgrounds. We conducted initial pre-screening meetings with parents to share information.

Measures and Procedures

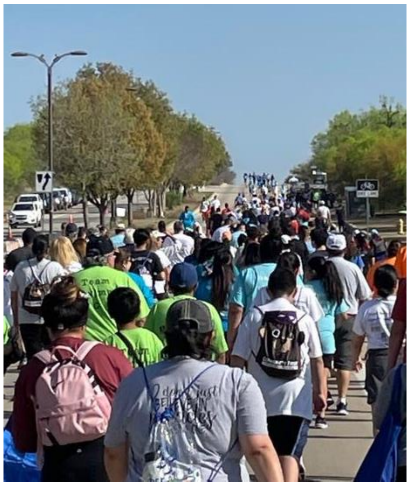
Planning and Initial Meetings

In preparation for research activities, our small research team had six weekly meetings for learning and coordination focusing on action research initiatives with two meetings focusing on ARDRAW research processes and the next steps to begin activities. Six parents met over the summer to discuss the action that initiated the process. In the meeting, parents shared ideas of “taking action” by telling their stories, creating resources for other parents, and meeting with community stakeholders. The group continued to explore the challenges from Phase I of the research study by focusing on four priorities 1) early intervention, 2) systemic barriers, 3) training needs, and 4) cost of services. This helped the group move into an action planning phase working with community stakeholders.

The statement was created collectively by participants at a planning meeting before activities:

"We want a community where children feel accepted and understood, not treated differently. A school system that works for all. Opportunities for individuals with autism to contribute as members of society. Inclusion in the community through education and awareness. Understanding across medical, education, and social integration. Healthcare providers that understand the urgency of early intervention and ongoing diagnosis. People understand that we are all equal regardless of diverse abilities. Parents working together to take action."

Connecting with Community Partner



Any Baby Can San Antonio is a local nonprofit that supports families in San Antonio, Texas, and the surrounding rural area, who have a child from birth through 17 years of age with medical diagnoses, including chronic illness, disability, developmental delay, or health risk. They do so by offering services in case management, prescriptive assistance, autism support, and training. Their Autism Services Program is designed specifically for families raising a child or youth diagnosed with ASD. The program provides parent education and support through a variety of services. By building relationships with community partners such as Any Baby Can, we started thinking of ways to design activities to support parents of children with autism. We met with their client specialist to collaborate focusing on initiatives such as recruitment, training, and activities. In addition, members of our small research team volunteered at various events including the Any Baby Can's Annual Halloween Social Event and Autism Walk Kick-Off, and the 18th Annual Walk for Autism (see Figure 2). The purpose is to build community-academic partnerships. Through these interactions, rich conversations took place among diverse stakeholders that revealed new knowledge and proved to be beneficial offering insights to advocacy-driven initiatives taking place on the ground level in the community. Through community-based participatory research, building partnership processes enhance relationships, build trust, and show a commitment to collective empowerment.

In this next section, I will focus on activities and events conducted and/or attended by our research team and community members.

Training Workshops

Prototyping with the Community - October 1, 2021

Figure 3: Parents prototyping community event

Figure 4: Parents and students learning about counternarratives

Data Jam Week was designed as a week-long event that took place at Any Baby Can as part of the Action Research for Community Health and Wellbeing grant initiative hosted by the University's action research working group organized by Dr. Alfredo Ortiz Aragon. Catherine Collins, a designer, and facilitator of Moxie Design Company traveled to San Antonio to facilitate activities. Ph.D. students working on action research initiatives, faculty members, and community members were invited to participate. Throughout the week, we focused on segments of the autism research study thinking about visual methodologies and storytelling, virtual environments, and health equity challenges. In one session, we engaged with UIW parents from our research study and parents with Any Baby Can to focus on prototyping methods to help them move from ideas to action (see Figure 3). Participants watched digital stories and learned about the concept of prototyping while developing their own prototypes by planning community events related to advocacy initiatives.

Changing Narratives: Story-based Strategy for Advocacy and Change - October 28, 2021

Participatory Research Week was designed as a series of training related to the Action Research for Community Health and Wellbeing grant hosted by the University's action research working group organized by Dr. Alfredo Ortiz Aragon. Raphael Hoetmer, a regional strategy advisor for the Americas for the Human Rights organization Amnesty International, and specialist in participatory methodologies traveled to San Antonio to facilitate activities. The purpose of the week was to expose Action Research to students, faculty, and community members. We invited parents of children with autism and community collaborators from Any Baby Can and Healthy Neighborhoods to attend a workshop called "Changing Narratives: Story-based Strategy for Advocacy and Change" by participating in person (see Figure 4). The idea is the status quo of inequities and injustices is sustained by narratives that present themselves as natural, yet are not. Fifteen participants attended the workshop learning how to create story-based designs directed to changing the narratives in society on the issues where social change is needed. The event focused on using participatory methodologies by connecting grant initiatives with broader participatory research for community health and well-being in San Antonio, Texas. The activities connected the links between participation, knowledge action, and advocacy, for the purpose of using participation in strategic practice. This method allowed participants to think of narratives from the parents' perspectives and policymakers' perspectives. Using this methodology, participants were divided into two groups, one focusing on parents of children with ASD, to discuss and analyze the dominant narratives around disabilities that parents face. Participants documented dominant discourses, audiences, counternarratives, and campaign messaging. The activity allowed participants to explore the impact of parent voice, equal access to services, the negative impact of losing services, awareness of human rights, and the creation of job opportunities for people with disabilities.

Activities: Rewriting the Script

Sharing of Parent Stories - Nov. 9, 2021

We invited parents of children with ASD to share stories of engagement with the healthcare system in a virtual environment with undergraduate students in the course "Cultural Issues in Healthcare" who are studying to become future practicing nurses, physical therapists, doctors, pharmacists, and other health professions. The story sharing was part of an action research process called "Rewriting the Script for More Equitable Healthcare" where community members and students worked together to help health providers become aware of inequitable health treatment of specific groups. By asking parents to share their stories with students who may encounter and serve future parents of children with disabilities, they may provide a better experience for these parents and their kids in the future. In this session, parents offered unique insights into challenges they faced by sharing digital stories created in phase one. In story circles, parents met with small groups of students and offered insights into the experiences while answering questions. Students were assigned to rewrite the narrative of healthcare challenges in a positive form using a health professional lens.

Rewriting Parent Stories for Positive Outcomes - Nov. 16, 2021

Parents met with students virtually to learn how their stories were rewritten into a positive form. In the session, all participants reviewed the stories, generated takeaways, identified key components of the story, and retold stories in a positive form after analyzing the conditions that would be needed to do so (for real change to occur). They entered breakout sessions to have short conversations and to better understand gaps in the stories that needed to be corrected for positive outcomes. Parents and students were then asked to create visuals such as educational material, pamphlets, or other media that can be used to continue a conversation away from the classroom and in the community. The workshop was designed to offer meaningful engagement between each group to generate knowledge and expertise to improve future realities.

Post-Activity Survey - Dec 15, 2021

A survey was sent to parents to gather feedback and reflections from the previous session (see Figure 5). The purpose of the survey was to better understand lessons learned, significant moments, methodology, exploration of ideas, and framing of new ways of thinking about advocacy roles.

Figure 5: Post-survey questions for parent participation

Survey Questions
a) Can you share lessons learned from your participation? Any insights or significant moments related to healthcare?

  - I learned that unless we educate healthcare providers on cognitive delays that impact patient education and well-being, they will continue throughout their professions not knowing they exist and how it affects the patient across the life span.
  - I noticed the students seem to really care about my story and were putting their heads together to come up with ideas to educate society on autism.
  - I learned that everyone has issues dealing with insurance, doctors, and therapies and it's a vast problem for those of us with medically fragile/dependent children. One thing I've learned on my own recently dealing with my son's epilepsy is "No" means to ask someone else. Most parents need to end the call when they realize they're not getting anywhere and call right back to get a different customer service agent on the line. Then nine out of 10 times they will have a different answer. I also found out just this week that if your doctor is great, he'll message the hospital himself to ensure you get what you need.
  - I was able to see from another set of eyes, listen and also reteach myself to think outside the box.
  - I think having a panel with different people to collaborate has helped me with different ways to approach the healthcare part. Also, a better understanding of the medical field to see how we can advocate for the doctors and nurses, etc., to have better training and a different process.

b) How can we continue collaborating with community members to begin conversations that explore challenges faced in healthcare using other methods?
  - Get them while the passion for their profession is burning. The earlier the better. Pre-med students and while in clinical rotations.
  - I do believe the visual approach is the best. There are many events that happen throughout the year and having a booth or something with information on autism would be a good start.
  - Any Baby Can is the best resource to reach out to the community. Also, my child attends a school where kids with autism attend come from all over Bexar and Comal County. They'd be great to reach out to as well.
  - Continue to collaborate and try to make changes even if small but a start. Maybe make a panel of people and make appointments with community doctors to see how we can help them improve their process, and their intake.

c) How do we continue exploring new ways of helping others understand the challenges that parents face in accessing programs, services, and support in the community?
  - Open forums with care providers, patients, and caregivers. We lack empathy in all of the healthcare so we need to get back to the basics of human compassion and understanding.
  - Continue speaking with parents and caregivers about what they experience raising a child/adult with autism.
  - Reach out to different hospitals and pediatric associations. Maybe put on quarterly or semiannual seminars (perhaps offer continuing education credits to attend) and invite a few well-spoken parents to write about their struggles so they can be presented. If doctors and hospitals understand what we go through, they'd have a little more understanding or compassion. Maybe invite employees from Medicaid/Star Kids, BCBS, UHC, Humana, etc., Or even offer to do Zoom presentations so the people we speak with understand they're just one cog in the wheel we have to overcome. I would even invite our legislators (especially since ABA isn't covered by Medicaid) to attend. We're an unheard population that really deserves representation from our doctors, therapists, insurance companies, and legislators.
  - Help with a current resource booklet, and online resource place. We have Any Baby Can but it's for ages 12 and under, we also need more places other than just one side of town and places that we can afford.

d) How might we support more parents to move into advocacy roles to support their own pursuits for adequate services for their children?
  - Social media groups. Autism groups. Show up at local educational/healthcare summits that are in the community for parent/patient education.
  - Support parents and caregivers. Listen and assist. Maybe even follow the steps/hoops they have to go through in order to even get services for their child/adult with autism. Some children never get diagnosed and grow as adults and then act out, and break laws, …because nobody figured out or knew they had a disability.
  - Supply a list of resources to parents (from insurance companies to therapists, to doctors/dentists/ophthalmologists that work with special populations, private, and charter

schools that take our kids, etc.) As well as tips and tricks provided by other parents who've lived through this. It can be distributed by Any Baby Can, Rock the Spectrum, Morgan's Wonderland, etc. Definitely, seminars (zoom or in person) will be the best bet. Reach out and collaborate with pediatricians, Medicaid, private insurance companies, and other parents to put together a nice resource for parents. The Epilepsy Foundation would be a big help as well. 1-3% of people suffer from epilepsy but 25% of autistic people suffer from it. Don't overlook them. Same thing with Fragile X, downs, Angelman, etc. There are a lot of organizations that reach a lot of parents!

- More support, more check-ins, parent advocacy training, start at the school, start when they get diagnosed. Almost like how we have ongoing therapy for the kids who have ongoing literacy. Advocate training while at therapy or at the doctor's appointment.

Classroom Art Gallery Walk - Dec. 21, 2021

Parents were invited to meet in person with students and bring visuals created and inspired by their stories (see Figure 6). A brief introduction was provided to the group explaining the gallery walk and story-sharing process. Prior to the activity, a video that I created in my “Research in Entrepreneurship” course was presented to all participants (see Figure 7). The video was designed based on my research agenda focusing on parents of children with ASD, coursework, and training from my Texas Partners in Policymaking cohort. Parents and students placed their visuals on the walls of the classroom to begin the gallery walk where all participants held conversations viewing the artwork. The event allowed participants to walk freely around the classroom before gathering in small groups to discuss lessons learned while concluding the activities.

Figure 6: Parents and students preparing for gallery walk event

Figure 7: A 6-foot painting presented by a student pursuing a career in health professions

Parent Check-In - March 4-8, 2022

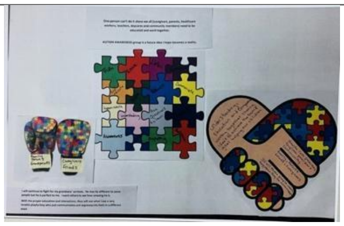
Parents were invited to individually check in with the research team through phone conversations. The purpose was to learn what has taken place since the last time all participants met and to share the idea of having a community planning event.

Planning a Community Event - April 14, 2022

Parents rejoined undergraduate students taking the course “Cultural Issues in Healthcare” who participated in last semester’s “Rewriting the Script” activity organized by my faculty mentor Dr. Alfredo Ortiz Aragón. The purpose was to ignite conversations with healthcare students on how participants might utilize the visuals created last semester in advocacy initiatives (see Figure 8). By explaining other ways to participate, parents and students can think of creating future events such as an art exhibit to share artwork and ideas with stakeholders. For this activity, parents and health professional students discussed advocacy by writing challenging stories and turning them into positive experiences in the healthcare system. The purpose of this activity was to explore opportunities to improve the chances of equitable health care in the community. Parents met with students to develop and refine ideas for advocacy using visual artwork created. Visuals were shared with both parents and students in small group settings to discuss the meaning of each artwork and how it could be used for advocacy and professional development purposes. Parents reacted to student stories by identifying the problem, vision, change needed, audience, and advocacy strategy.

Figure 8: Sample of Parent Artwork and Descriptions

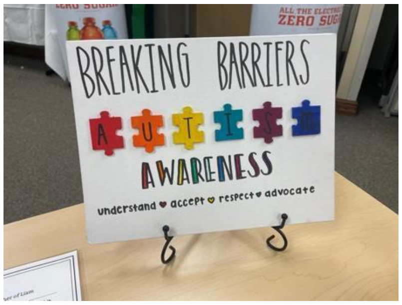
Parents	**Artwork**	**Description**
Artwork A		This side of the pamphlet shows the ribbon for ASD awareness and the resources that have helped me learn through the years all about autism. I used the ribbon to catch the audience’s eye. I wanted to get the ball rolling, so I added resources that I know get the audience in the right direction. Let's get moving everyone.
Artwork B		The proverbial David vs. Goliath is a parable that most can understand and identify with, an individual perceived to be weaker versus a stronger adversary. When a child is born everyone has the joys and challenges of how to care for and raise the child, but when you get a diagnosis of ASD, your whole world and direction change. Parents often have to battle medical, educational, and financial systems that were put in place by individuals that don't use the system, so when the norm is questioned, there is often resistance. Our group was very insightful and asked, "Why not?" Why isn't there more flexibility within the system? Parents are told they're the experts regarding their child's needs. Then why isn't their perspective just as valid as the doctors, teachers, and policymakers? Evolution within a system is great, but revolution can bring about real change by and for the individuals who will benefit most. The truly brave choice is to ask, "Why not?"

Artwork C		No description
Artwork D		No description
Artwork E		The description for this artwork reflects a mother holding her child. The mother represents voice, nurture, and unconditional love. She is sitting like a bird in a nest which symbolizes security, hope, and protection. The darkness is surrounded by words that influence her daily life. I want people to see the visuals and stop to read the messages. I used some takeaways from the student transcripts and the findings from the previous ARDRAW report. Due to the struggles of moving schools, searching for answers, changing careers, and paying for healthcare, she feels emotionally invested in caring for her child. She is on the verge of information overload and needs flexibility. As a parent advocate, she understands that her story is her biggest purpose and believes in positive solutions. She knows that help and aid come in many forms. Active listening, compassion, and trust can go a long way when speaking with her.

Community Art Exhibit (April 27, 2022)

Parents and students participated in an art exhibit at the Children's Hospital of San Antonio showcasing their artwork and having dialogue to help "Rewrite the Script" for community-engaged professional development for more equitable health care. Guest participants included family members of students, healthcare professionals, university administrators, and hospital representatives. This event began with students and parents displaying their artwork for all participants to view the pieces and read descriptions (see Figure 9). Students stood by their artwork and described to viewers the inspiration to create their artwork based on the stories of parents of children with ASD.

Figure 9: Art exhibited by parents and students pursuing health professions at the Children's Hospital of San Antonio



Parents also describe their experiences and reflect on the process to design their pieces. Afterward, representatives from various organizations shared insights and appreciation for attending the event. Next, all participants took part in a World Café activity, a roundtable open discussion, where small groups had conversations focusing on questions shared by a facilitator (see Figure 10). The purpose of the events was to have discussions on health equity issues in the community with attendees. To complete the event, a member at each table was designated to present on behalf of the group lessons learned from the event.

Figure 10: World Café questions

Questions
a) What experiences do we have around the table with autism and what health equity issues stood out to you in the student and community art and narratives? b) How are you understanding the role of health professionals in addressing these issues? c) What actions can we take in the next three months to become better allies to communities who face inequities in healthcare?

Feedback and Reflection Survey (May 16-23, 2022)

A survey was sent to parents to gather feedback and reflections from the series of events that took place in the rewriting of the script process with health professions students.

Figure 11: Post-survey questions with parent feedback and reflection

Survey Questions
a) I LIKE... (something you appreciate from your experience in the Rewriting the Script process with Health Professions students this semester and last) ○ how fearless the students are. ○ that we can share personal stories and show how families are impacted by healthcare professionals who do not care enough or have a good understanding of our situations. ○ the enthusiasm of the young minds to help make a change. b) I WISH… (constructive critique about the Rewriting the Script process) ○ more students and parents were more vocal about their perspectives and observations. ○ more current hospital/clinic personnel can attend our meetings and showcases. ○ we had more opportunities like this with students. c) I WONDER... (a thought or question looking forward) ○ where will these students be in two years? Where will our parents be? ○ how we can get new cohorts or residents to have us present yearly during their rotations so they keep families in mind during their care ○ is there a way to continue the learning process even after these students finish the class and continue with future classes? d) What are your main lessons learned or takeaways from your participation in the Rewiring the Script Process?

- Hope. I can't get away from that word. There isn't a lot of hope on our journeys.
- That we are making waves. Even if they are small ripples right now.
- Always think outside the box, ask questions, and listen.

e) What insights do you have related to healthcare or health equity?
  - How pervasive inequity has become and how fearful we appear to be to make dramatic changes to the system. We need to be fearless!
  - As a healthcare provider, I do see the inequality with disability and race. Not as prominent as 10 years ago when I started but still there.
  - I feel that we are all in this together literally, we each are the missing piece to help with equity.

f) What insights do you have about the role of advocacy to attain equitable health care and services for your child with autism?
  - All of us need to constantly share our stories, healthcare professionals, caregivers, and anyone who consumes the healthcare system, and we need to move from advocacy to action.
  - I find when healthcare providers know the classes I've done pertaining to autism. They come from a point of more respect. Hearing I am a nurse makes them more open to my ideas than before. I can sense the attitude of they know more without knowing my own education of autism over the years.
  - Not to be embarrassed about something you don’t understand. Always ask questions and make sure to also be heard when voicing your needs for your child.

g) What new ways might we explore to help others understand the challenges that parents face in accessing programs, services, and support for their children with autism?
  - Maybe have parents share video clips of their experiences. This would require people willing to be very vulnerable. Also, I think more face-to-face contact. A lot is lost when you can't read body language and have close contact.
  - Understanding that there are many resources (awesome), but resource overload can be thrown at families and providers aren't aware of resources pertaining to certain times of development or what insurance will cover, etc.
  - Have centers for resources in more than one area of the city. Autism schools and autism daycares are a huge need. Not many places accommodate children with special needs. Also, having community meetings from all sides of town with city officials to see what we can create to help make more of our communities helpful to our special needs community.

h) Keep or increase (What would you keep about the rewriting the script process or do more of?)
  - More face-to-face interaction, it's too easy to act on a screen.
  - Keep up everything! Increase social media presence of the work being done in UIW social media and other autism platforms.
  - Continue to increase!

i) Change (What would you change about the rewriting the script process or do less of or remove?)
  - I don't feel confident enough to give my input as to what to change. I think really honing in on the process and refining it based on the participants will work well.
  - No change is needed other than making more noise with social media platforms.
  - Just to continue every semester so that this education spreads and helps our future health care and the autism community.

j) Create (What would you add in as new to the rewriting of the script process that it did not include?)
  - We need to include community leaders, how can we engage the changemakers in the process?
  - Nothing to add here.
  - Maybe more parent/student meet-ups on hand learning experience with the child.

k) Is there anything else you would like to share?
  - This is a great partnership! Have y'all considered sharing with local media? Maybe once we can get local leadership involved?
  - My husband was amazed that we are able to talk with healthcare professionals so easily in the setting of understanding there are pitfalls that need to be addressed. He felt it was a very productive platform.
  - The people who put this together have opened new doors for many people and should be proud of all the hard work created.

Analytic Plan (Data Collection)

Our research team used Zoom web conferencing to audio-record videos for online sessions and a recorder for in-person activities which were transcribed verbatim. We used qualitative research data analysis to implement key actions and document data generated from each action. Using this approach, we analyzed data to carry out participatory analysis to determine the next rounds of actions. We offered parents surveys to capture reflections. Participants wrote reflections using a Padlet board to share information. Information was captured after each meeting and data was presented back to participants. The research is used to explore findings to determine the results of the study.

3) Findings

The findings of this research study are relevant to the methodology used to examine a parent's experiences. Our approach to developing the findings uses a qualitative approach to connecting patterns and organizing categories with sample quotes from data collected. Participants' names in the statements below have been changed to protect their identity.

Amplifying Voices: Hearing Unheard Populations

Parents expressed concerns about addressing healthcare needs in Phase I by constantly retelling their stories to seek a diagnosis for their children in order to access services. In our next phase, by focusing on healthcare challenges, parents shared their stories with undergraduate students pursuing careers in medicine, nursing, rehabilitation services, and other healthcare-related fields. Through the story-sharing process, parents learned that students entering health professions were mostly unaware of the challenges they faced, yet with awareness through story sharing students became more convicted to advocate for parents and future patients. When asked, "How do we continue exploring new ways of helping others understand the challenges that parents face in accessing programs and services, and supporting the community? One parent wrote:

> *"Reach out to different hospitals and pediatric associations. Maybe put on quarterly or semiannual seminars (perhaps offer continuing education credits to attend). Invite a few well-spoken parents to write about their struggles so they can be presented. If doctors and hospitals understand what we go through, they'd have a little more understanding or compassion. Maybe invite employees from Medicaid/Star Kids, BCBS, UHC, Humana, etc. Or even offer to do zoom presentations so the people we speak with understand they're just one cog in the wheel we have to overcome. I would even invite our legislators (especially since ABA isn't covered by Medicaid) to attend. We're an unheard population that really deserves representation from our doctors, therapists, insurance companies, and legislators." - Parent*

Opportunities expressed by parents include sharing their stories with healthcare professionals by having presentations, professional development events, and training workshops. Through the process of wanting to be heard, there were suggestions of inviting community and state representatives of various organizations to discuss health equity challenges and opportunities.

Finding Voices: Building Relationships for Advocacy

Parents expressed how they are growing from each experience which is translating to their daily lives caring for their children. By sharing their stories with students, parents are seeing the impact of how their stories can be used by taking action in the community. One parent shared how she is advocating for her son at various school district meetings. This is what she had to say:

> *"I want to expand, to learn, and have an open door. People get discouraged. When I go to the community, I have to think of disabled children. To build relationships, you have to get involved. To keep it going, you have to show you are there for our children." - Parent*

Another parent shared how she got involved with an advocacy training program that educates parents of children with ASD, noting there is a need for a program like this in San Antonio for parents.

> *"I'm feeling great. I love that you guys are being open to our stories and open to learning how to modify your education and modify your future practices in whatever healthcare professional aspect that you will be in because you guys have an understanding that autism is throughout the lifespan, and you will eventually be seeing autistic and other intellectual disabilities throughout your healthcare. And you have to make a point to tailor your training, your education, your teachings with the patient and their care providers."*

When parents had conversations with students and other members of the community, they soon realized that their voices can make a difference. These reflections highlighted the importance of parents becoming aware of health inequity and moving into advocacy roles across the lifespan as their children journey.

Voices for Change: Sharing Stories

Stories can offer a new outlook on the situation by rewriting a negative experience into a positive one. Parents feeling heard by students entering health professions through active listening brought a new hope moving forward. From the Rewriting the Script activity, one parent expressed the following:

> *"Going through it with the students in the course, I feel proud. I feel so honored to be working with them and seeing that our stories are making a change and that…these young adults are listening and are willing to make the change and they have good mindsets and their careers and they know what they want and this just allowed them to be more aware and go in with an open mind and allow us as parents who even though we've experienced, you know, the backstory that there's a way we could still make a change and still change, for, make a change for us, and for other community members so that our*

> *stories, allow somebody else not to go through what we went through, kind of thing. So that was awesome. So, I appreciate this. Thank you."*

Parents expressed feelings of being honored by working alongside students collaboratively to educate and share new knowledge that could one day help future parents.

> "*I appreciate, you know, the students that I talked to in my group, they were able to identify problems and had a vision and really grasping, like, you know, what's going on and listening. And I know, I talk when I, when I share, I kind of share a lot. And I just want to make sure that I'm sharing good information. Hopefully, it could be helpful later. And I just appreciate the time that they're taking everybody's taking to work on this. It's really important…and I think just the fact that if, you know, we were able to help someone understand what experiences were going through, and they are starting to become more aware of it, that it would help them in the future, working with future patients or are working in a pediatric unit, because also didn't mention we have an adult you know, adults have autism too. So, anything that can help make you better as a healthcare professional provider...I'm just happy to be with y'all today."*

Parents expressed excitement by seeing their artwork created through the inspiration of their stories displayed at community activities. There is an appreciation of comradery by participants co-learning in the community.

4) Discussion

Using Storytelling for Advocacy Initiatives

Parents sharing stories of challenges in accessing federal programs, services, and support with community members can offer a new outlook based on their lived experiences. Through the Rewriting the Script process, bringing parents and students together offers a broader engagement into understanding the autism community and the perspective of health professional students beginning their journey as they enter into a career field. Using the model “Rewriting the Script” and building relationships across groups there are three main steps 1) storytelling, 2) re-writing the script, and 3) taking action. Storytelling offers the sharing of adverse, inequitable experiences with the healthcare system. Re-writing the script involved collectively re-writing the script to a more positive version. Taking Action creates visuals from the stories and taking actions with those visuals. Parents and students joined together to share stories and think about the retelling of stories from a negative to a positive form. In some cases, this includes stories that display challenging experiences with the healthcare system. Understanding how people are treated by directly engaging with the next generation of healthcare professionals can help them figure out how they can engage with community members directly before entering the field. This includes thinking of better ways to allow parents to feel heard and amplifying their voices to access the services and care needed for their child.

Through this process, students engage directly with parents of children with ASD to learn about issues in healthcare that directly affect children and their family’s quality of life. By using participatory data visuals, such as artwork, we provided a space to create, brainstorm, and offer conversations on advocacy initiatives offering new messages that can be shared with community members to raise awareness. The idea is to change the narrative from a poor to a positive experience thinking about equitable health care for the larger community. Trying new methodologies, such as rewriting the script, allows target populations facing challenges, such as parents of children with autism, facing adverse or inequitable experiences to connect with others in the community. Rewriting the story to a positive version allows participants to think of the counter narrative focusing on how events should have gone when the process is working correctly.

Participatory Data Visuals as Conversation Starters

Turning artwork into actionable experiences allowed parents and students to strike up conversations with other community members asking questions such as "What do you think about this visual that I created?" By offering a gallery walk and presenting artwork, participants could have rich dialogue reflecting on critical issues and reflection focusing on advocacy. The visuals themselves become the conversation that starts striking up conversations. For example, one parent created an image expressing her feelings when trying to access services in a hospital and school setting. The visual has a large figure of a person standing between a family and buildings representing places that offer services (see Figure 9, Artwork B). The imagery of the artwork tells the story which connects back to the community member's story. The visual power of the artwork offers new insights which can support an inquiry process to ask more questions by the viewer. Another parent offered a visual using boxing gloves decorated with puzzle pieces. She mentioned how she has to use these sometimes symbolically when fighting for services. She also created a visual with hands, one colorful puzzle design, for the desire to unite with others by shaking hands. The images offer a powerful set of messages that speak with the artwork. Bringing the artist and viewers together to have these conversations can shine new insights into the story-sharing process.

Connection to Social Security Administration

The Social Security Administration's Supplemental Security Income (SSI) program offers financial support and services to families of children with disabilities who experience economic hardship (Social Security Administration, 2021). According to *Fast Facts and Figures about Social Security* statistics, over one million disabled children in the U.S. are offered financial benefits through the SSI program (Social Security Administration, 2020). Yet, access to the SSI program can be out of reach for children with ASD based on parental income level requirements, even when parents struggle to pay for the high cost of medical and therapy services (Vasquez, 2021).

In Phase I of the research study, we wanted to better understand how parents of children with ASD gain access to federal programs, social services, and support. This led to an inquiry process of hearing parent stories through digital storytelling and learning about their experiences as they navigate complex systems. A model of the parental experience was created in Phase I that helped us discover six major areas affecting access to services. One particular area focuses on the healthcare needs of parents as they are constantly retelling their stories to gain access to a diagnosis and support services. Parents provided examples of long waitlists and cumbersome intake requirements. They expressed concerns about barriers they faced when contacting healthcare providers or organizations in the community for assistance and how obtaining a diagnosis is vital to early intervention approaches.

In Phase II of the study, parents shared their stories with students pursuing careers in healthcare with the understanding that medical professionals can assist parents with access to services. Parents shared their stories of caring for a child with ASD and described the challenges they have faced in the healthcare system. The research activities allowed us to learn how various methodologies using action research and art-based approaches can offer rich dialogue and new perspectives from all participants. Programs such as the Supplemental Security Income (SSI) can utilize these methods to offer a new lens for collaborative interventions by including all stakeholders in the process to address barriers that affect access to the program. For example, the Social Security Administration can utilize this methodology to explore the parental pathway of learning about the SSI program, benefit eligibility, application process, return to work incentives, income reporting processes, and other requirements. Collaboration through the research study with parents, students, researchers, healthcare professionals, and community members offered a multilevel approach to interventions in a co-learning environment.

Limitations

Limitations encountered with the research study included time constraints among participants often attributed to childcare, work schedules, etc. Being able to accommodate participants with busy schedules is important to consider when working with community-based participatory research. To address these challenges, we continued actively communicating with parents to find dates and times that were feasible to meet the needs of their schedules. It’s important not to get flustered when trying to stay on a timeline, instead be adaptive and emergent through the process. We accommodated participants by offering hybrid approaches both in-person and online.

5) Summary and Conclusion

Rewriting the Script offers participants an opportunity to change a negative experience into a positive one by writing a counternarrative with all participants. Using approaches such as participatory data visuals can allow participants to share new ideas and new information with community members to expand on conversations in support of advocacy initiatives. The experiences faced by parents can be shared by inviting others to learn about their experiences through storytelling. The storytelling process can offer a cross-collaboration and transfer of knowledge that helps all participants gain a deeper understanding of the challenges that parents of children with autism can face in gaining access to services and support to care for their children.

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