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ORIGINAL PAPER

What it Takes to Raise Children with Autism in a Rural State

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Abstract

Parents of children with autism living in a rural state face unique challenges based on their location. These include barriers to diagnosis and treatment, driven in part by scarcity of professionals familiar with autism and long distances between services providers and family residences. Instead of focusing on these barriers, which are well known and researched, we utilized a strength-based technique known as Appreciative Inquiry (AI) to inquire how parents view and experience success for their child with autism in a rural state. Our investigation was conducted with 22 parents of children with autism ranging in age from 30 to 60 years using semi-structured interviews. Data were analyzed using thematic analysis. Results of our analysis indicated that parents envisioned and promoted success for their child over time through: (1) developing skills, (2) integrating (their) child into community, (3) building relationships, (4) advocating by parent and child, and (5) adapting to their new reality. Our findings showed that parents in a rural location define success based on their existent resources and support systems provided by clinicians, school personnel, and most importantly, support from the larger community (e.g., other parents). Parents in our study showed that behavioral interventions are not the only solution.

Keywords Autism · Appreciative inquiry · Rural · Success · Parents

Autism spectrum disorder (ASD) is a developmental disability characterized by deficits in communication and social interaction as well as in restricted and repetitive patterns of behavior. Autism symptoms can range in severity levels from mild to severe (American Psychiatric Association 2013). According to the Center for Disease Control and Prevention (2016), the prevalence of autism is increasing in the USA and is now estimated to affect 1 in 68 children (Baio et al. 2018). Indeed, ASD is the fastest growing pediatric neurodevelopmental disorder in the USA (Baio 2012). Early diagnoses of ASD and subsequent interventions have been found to be especially important for decreasing the symptoms of ASD and improving child outcomes (Christensen et al. 2016).

Despite the rapid increase in the public health burden associated with ASD, as well as a push for earlier diagnosis, there remains many well-documented health disparities related to screening and diagnosis, as well as access to services (Durkin et al. 2015; Moody et al. 2017; Parikh et al. 2018; Siu et al. 2016). For instance, there are numerous and well-documented disparities related to racial ethnic categories (Gibson 2007; Magaña et al. 2013; Mandell et al. 2002; Williams et al. 2015), and socioeconomic status (Daniels and Mandell 2014; Fountain et al. 2012). One group facing disparities has received relatively little attention: children with autism living in rural areas. Like other groups, children living in rural areas face many health disparities in their ability to obtain an autism diagnosis, and are, therefore, likely to be diagnosed later than their peers in urban areas (Daniels and Mandell 2014; Mandell et al. 2002).

These disparities are likely due to a variety of factors, but most likely include challenges related to the unique geographic barriers to accessing autism-related services in rural areas. For instance, rural communities often suffer from health care

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shortages that cause residents to travel vast distances to find care providers. In Wyoming, a largely rural and frontier state, there is not a single county that has sufficient healthcare providers for primary or mental health care (Health Resources and Services Administration 2016). As a result, many families must travel great distances, often out of state, to receive appropriate services. Moreover, in many large western states, travel can become impossible through mountain passes and remote roads for much of the year during inclement weather. Further, there is often limited public transportation in rural communities. This includes limited commercial air service to larger cities, minimal commercial bus service between cities, and no passenger rail service.

Given the dearth of service providers for autism, there has been an increase in interest on rural health and how to improve health outcomes in these communities (Antezana et al. 2017; CDC 2016; Skinner and Slifkin 2007). Much research focuses on documentation of these barriers without providing concrete solutions to these challenges (Elder et al. 2016; Mello et al. 2016; Paul 2017). While documenting these deficits and barriers is critical, it does not necessarily provide guidance on how to manage these challenges. Moreover, research that merely documents barriers endemic to rural communities often struggles to provide clear guidance on how to overcome those challenges. As a result, despite this interest, rural health disparities persist for those with ASD.

Indeed, there are a variety of strategies that families use to support their children with ASD in the absence of traditional healthcare. For example, clinicians often recommend an Early Intensive Behavioral Intervention (Mottron 2017; Reichow et al. 2012) such as Applied Behavior Analysis (ABA; Lovaas 1987; Lovaas and Smith 2003) or the Early Start Denver Model (ESDM) (Rogers and Dawson 2010), despite the fact that there are usually no providers available in rural settings to provide these services. However, parents choose from a wide range of services including occupational, speech, and physical therapy; sensory integration therapies; complementary and alternative medicine; diet changes; and other non-validated approaches (Patten et al. 2013). Indeed, the most commonly used interventions are occupational, speech, and physical therapy, perhaps because insurance or Medicaid will cover these interventions more easily or that they can be delivered in educational settings (Koegel et al. 2012; Zhang and Baranek 2016). That parents explore interventions that do not have a clear evidence base does not mean that their children do not derive benefit from those interventions.

Beyond evidence-based interventions, parents may also employ a variety of personal coping mechanisms to help manage the challenges of having a child with autism, including both problem- and emotionally focused strategies (Pepperell et al. 2016). For example, increasing social support is incredibly important for parents, especially mothers of children with autism, to reduce stress and isolation, and to increase access to resources (Ekas et al. 2010; Reinke and Solheim 2015). This can include a combination of informal (family, friends) and formal (professional) supports (McIntyre and Brown 2016) and may be developed through online platforms (Mohd Roffeei et al. 2015; Reinke and Solheim 2015). Further, religious observance may help families cope. For instance, over time, religion became a primary coping mechanism (surpassing the use of treatment services and family support) in some families of children with autism (Gray 2006). This particular coping strategy may be used when other coping strategies are no longer effective; particularly when they feel unsupported, exhausted, or isolated (Gallagher et al. 2015).

Parents have also been found to use several coping strategies that help support their own wellbeing. For instance, self-compassion, defined as “being kind to oneself in times of difficulty, recognizing the shared nature of human suffering, and being mindfully aware of negative thoughts and emotions” (p. 938), is associated with increased well-being (Neff and Faso 2015). This can include taking time for oneself (Kuhaneck et al. 2010; Paynter et al. 2018), engaging in hobbies, exercise, time with friends, or time alone (Pepperell et al. 2016). Parents have also reported using mindful parenting, in which they embrace the non-linearity of life and engage in emotional work to deal with feelings of guilt, sadness, and perceived stigma related to their child’s disability, to help manage their lives (Lee et al. 2015). Further, mothers of children with disabilities have reported accepting their child’s limitations, but using their child’s strengths to fight against the negative opinions of professionals and peers (Lee et al. 2015). They also try to build on their child’s skills by continuing to seek for solutions to problems even if there are no known cures (Lee et al. 2015).

Taken together, these findings suggest that parents will use a variety of strategies to achieve a successful outcome for their children and families more generally, regardless of whether that includes traditional behavioral interventions. However, little is known about what it means for families of children with autism to successfully raise their children in the context of healthcare shortages or how they achieve that. Put another way, it is unclear how parents with children with autism define success when raising their children or how they promote the successful outcomes they desire, especially in rural settings. Our study adds to the literature by using the Appreciative Inquiry (AI) technique (Hammond 2013), a qualitative research design that focuses on the factors that allow respondents to achieve success; however, it is personally defined. This approach differs from other qualitative investigations that only focus on barriers, and as such, may provide insight on how individuals living in these circumstances can better achieve the life they desire (Reed 2006). Overall, this project explores what makes certain parents successful in raising a child with autism in a rural state.

Method

Participants

The participants in this study were recruited through purposeful sampling. Purposeful sampling places emphasis on the in-depth understanding of specific cases from which the investigator can gain insight (Patton 2015). In purposeful sampling, participants are chosen based on a specific criterion. The inclusion criteria for this study included (1) self-reported parents of a child with ASD, (2) residence within the state of Wyoming, and (3) over the age of 18. We recruited participants through several sources, including a departmental listserv which was distributed to professionals and community members, social media platforms (e.g., Facebook), and existing relationships with family groups throughout the state. Individuals who expressed interest in participating were encouraged to share this opportunity with other parents of children on the autism spectrum. Our final sample consisted of 22 parents. Most respondents identified as White with only one identifying as Hispanic/Latino and one as biracial and this was consistent with the state's demographics. The majority (95%) of participants were mothers. Parents' age ranged from 39 to 72 years while the children demographics included 6 females and 14 males with average age for child being 14 years.

This research was conducted under the approval of the University Institutional Review Board. Throughout all phases of the research process, participants were treated in accordance with APA Ethical Standards (American Psychological Association, 2017).

Procedure

This research was carried out by the Wyoming Institute for Disabilities' (WIND) research core. WIND is a University Center of Excellence for Developmental Disabilities (UCEDD) for the state of Wyoming and is an academic unit in the College of Health Sciences. Data was collected using semi-structured AI interviews to explore parents' subjective experiences and beliefs about what success means to them. The AI interviews were conducted from October 2016 to October 2017 and written informed consent was obtained prior to all interviews.

All interviews ranged in time from 30 min to 1 h and were completed via video conferencing or telephone. Participants were provided with a US$20 gift card for their time. Finally, interviews were transcribed in full, and memos were written simultaneously. Memos were used throughout the coding and analysis process. To ensure the confidentiality of our participants, all audio/video-recorded interviews were deleted following verbatim transcription. Identifying information was removed from all transcripts, and participants were assigned a unique identifier (pseudonym) in place of their name.

Measures

Data was collected in the form of a minimally structured interview guide. The interview guide was based on the AI model and was designed as the first step in a process of developing community interventions to support ASD in underserved rural settings (Norman et al. 2013). Prior to implementation, the interview guide was reviewed by several external AI experts during one of the author's (EM) training on the method. This ensured that the guide met the standards of AI, which is to have an intentionally broad prompt, "Please tell me about your child with autism, and what has been working for your family." Following this initial prompt, participants shared their experience and story with minimal interruptions from interviewers. Interviewers asked follow-up questions for clarification and redirected the conversation if it veered away from the participant's success story. Common follow-up prompts included, "How did your child's ASD start?"; "What made you realize you needed help for your child?"; "What prompted you to get support?"; "What resources were available?"; "What kind of interventions did you receive?"; "What decisions or personal strategies do you use to help manage your child's ASD?"; "Where are you now with your child's ASD management?"; and "How do you define success?". Basic demographics were collected after the interview.

Data Analysis

An AI design was employed in this study as a qualitative approach for exploring success among parents of children with autism in the rural state of Wyoming. AI is based on the principals of positive psychology, action research, and organizational development. It invites participants to discuss their successes rather than focus on barriers or problems (Reed 2006). AI was originally designed to challenge traditional paradigms of organizational structure and has been used extensively in business, non-profit, and health organization settings (e.g., Kusch et al. 2013). More recently, AI has been used in health care research to better understand existing strategies that promote health and wellbeing (e.g., Hennessy and Hughes 2014). The Appreciative Inquiry approach was selected for this study to better understand what success means for families of children with autism, as well as how they achieve this in a largely frontier state with few resources.

Transcriptions were analyzed using a thematic analysis approach (Braun and Clarke 2006). The thematic approach to analysis involves finding reoccurring patterns or themes across interview data that reveal participants' shared subjective experiences. The research team chose a thematic approach because we were interested in participants' emerging perspectives and processes as parents of children with ASD. Moreover, the thematic approach aligned with the purpose of our study which was to explore participants' definitions and experiences of success for their child with autism.

Steps were taken in the coding process to ensure credibility of the findings. The research team comprised of an interdisciplinary team with two faculty members: RS (social and administrative pharmacy) and EM (social psychology and developmental cognitive neuroscience) and two doctoral candidates: BR (sociology) and ES (counselor education and supervision). One of the team members identifies as a family member of an individual with autism. The richness of the diversity of perspectives provided a unique lens to this study data. We also made attempts to enhance the credibility of findings by taking a team approach to data analysis.

Throughout the coding process, coders revisited, revised, and collapsed themes based on multiple discussions and feedback from the research team. The coding process was iterative and dynamic in nature. Coding was done both manually and via qualitative research software (NVIVO 10®). This software enabled both line by line coding as well as coding by question. To begin, the authors RS and ES read transcripts to familiarize themselves with the data. During this initial coding stage, the coders used line by line coding to collect codes; next, these codes were assembled into potential themes. Following initial coding, the coders met to review and discuss the emerging themes. These themes were compared and revised as necessary. After the initial discussion, the primary coders returned to the transcripts and determined if new themes emerged. Once the researchers determined that no new themes emerged, the team defined, refined, and condensed themes. Finally, all members of the research team met to discuss and organize the data into the final themes and create rich descriptions of these themes. These themes were obtained after all authors provided consensus on the study findings.

Results

The purpose of this investigation was to explore parents' views and experiences of success for their child on the autism spectrum while living in a rural state. Results of our analysis revealed how parents envisioned and promoted success for their child with autism in a rural state. Our results were placed into the following five themes: (1) developing skills, (2) integrating (their child) into the community, (3) building relationships, (4) advocating by parent and child, and (5) adapting to new reality. These themes, along with their subthemes, are described below with text exemplars.

Developing Skills

This theme represented parents' vision of success through their desire to have their child develop skills over time. Parents overwhelmingly spoke of their hopes for their child to grow towards *independence* and obtain *self-regulation* skills by being able to communicate and express their emotions. These distinct skills formed the subthemes to further discuss parents' perception of success in this area. Parents' personal definition of success was contingent on their child's functioning level.

Independence

Parents stated that they hoped their children will grow towards independence. It was important to note that parents' definitions of independence differed based on their child's ability, age, and the severity of ASD. For example, Samantha expressed her hope for her child to develop the ability to be independent by making choices and decisions for himself, "I want him to move towards independence as much as possible … one way that happened for us this year was by allowing him to pick his own classes. I let him choose whatever he wanted and I encouraged him to make his own decisions." Samantha was facilitating her child's ability to be independent by giving him choices and creating situations in which he had to make his own decisions. Although this process may take longer for a child with autism, this parent believed his ultimate success was intertwined with his ability to make choices for himself and have some level of independence. Similarly, Ashley expressed her views of her child's independence as the ability to take care of himself, "… he is independent as far as taking care of himself, he keeps track of his homework, and he did some lawn moving for people. He is very responsible and he is respectful and kind. I see him moving towards being able to being independent." Again, the importance of this skill of being independent in school as well as other tasks was important for parents at present but also as a future goal of success for their child.

Self-regulation

Parents also expressed their desire to have their child develop self-regulation skills. Their visions of success for their child involved their child's ability to first notice their emotions and further to develop the ability to find ways to control those emotions/behaviors. For instance, Amy, like many other parents in our study, expressed her desire to have her child develop these skills.

> Success would be for her to start figuring it out for herself. Here's what my hope is ... that someday she starts noticing that for herself, like oh I am clenching my fist, what does that mean? Oh, that means I am really frustrated. And why am I frustrated? It is because there's too much noise, and what steps can I take to alleviate

> that for myself? My hope is that someday she is able to do all of this on her own.

Integrating (their Child) into the Community

Parents wanted their child to be an active and included member of their community. For most parents, living in a rural location meant they developed close ties with their community. Their desire to have their children become an active and included member of the community reflected a deeper desire for their child to be a part of the communities in which they belonged. Parents found success for their child through integrating them into the community by promoting active participation and receiving support and resources from community members.

Parents viewed success through their child's active participation in the community. This often included taking their child to after school classes or encouraging them to be on teams. In the quote below, Samantha expressed the support and inclusion her family felt from the activities at their local recreation center where her child was an active participant:

> Our biggest success with my child is her participating in the community. We needed to make sure she was integrated into the community. Our rec center has an amazing after school program with typical peers. And our rec center is really good and they understand they need to meet the needs of all kids. So they were great with me and working to figure out how to make it helpful for her. And they never complained about having her and she gained a lot of social skills and public behavior type skills. She has grown up in the community and they know her. And to be genuine in their help is so nice.

Parent's ideas of success related to integrating their child into the community varied by the age of their child; however, their child's integration into the community remained an important component of their child's success. Regardless of their child's age, parents overwhelming spoke to the importance of using the community to promote their child's success. Parents valued how the community aided their child in reaching his or her full potential. Additionally parents mentioned the support they received from community members who knew and understood their family and their child on the spectrum. The support from community members was crucial in their journey of integrating their child into the community.A parent wanting their child to be an active and included member of their community was exemplified in the quote below by Cassie.

> At the minute, in the program he is in at the high school, they focus on being an included, interactive, responsible, member of community. I hope that my son will be an inclusive member of society, within the community, whatever community we are in.

Another parent expressed her hopes for her child to become a productive member of the community through having a job that brought meaning and purpose in her life. Monica: "My hope for her as an adult would be able to, have a job so, she could live comfortably. I would hope that she has a career and has relationships that are fulfilling to her in whatever form that is."

For several parents, living in a rural community was a protective factor. Several parents felt that living in a rural community provided a sense of security which aided their ability to promote success for their child. Both Anna and Katy in the quotes below, described the safety and comfort they felt knowing that community members were familiar with their child and were willing to step in if their child needed help.

> Anna: Now, we live in a better and safer neighborhood, they have monthly and community events that people can do downtown. Smaller town feel and bigger community connectedness. When we first moved in, the church community helped us moved in and made us feel welcome. The school bus driver is more like a teacher and she is really aware of what is going on and everybody they ride with is their friends.
> Katy: We are definitely progressing in a different way. ... because we live in a small community here, there are more opportunities for him to be more independent. You know; because I would never, let him loose when we were in a bigger city. Here, he runs all over and talk to people. I feel comfortable that he isn't going to disappear or get in trouble.

Overall, parents in this study promoted success for their child through connections and support in their local community. Community activities and resources enabled their child to be more socially connected to others, work on social skills, and develop friendships.

Building Relationships

Parents described ways they were able to promote success for their child despite the many barriers they faced while living in a rural state. Parents made progress through connections and relationships with others including parents of children with autism, family members, friends, and professionals. These connections were fostered through both in person and virtual meetings, discussions, and support groups. Through these meetings and groups, parents gained practical information as well as social and emotional support.

With Other Parents of Children with ASD

Parents promoted success for their child by building relationships and connections to others. While speaking with parents, it was apparent that they sought out ways to connect with other parents who also had a child with ASD. This enabled them to feel like they were "not alone" and helped to normalize their experiences. One way parents fostered these was through the use of social media. For the majority of parents, social networking was a means for them to reach out and become connected to others who shared their experiences. These networks were particularly helpful when parents felt frustrated or were having challenges.

In addition to online connection, parents described the benefits of in-person support groups. While speaking about these support groups, parents discussed the need to connect with other parents of children with autism. This made them feel like they had others who "get me" in a different way than professionals can offer. Leah, for example, said the following:

> You know, I used to refer to the journey our family has been on has been a lot of running with the occasional obstacle. Every time I run into a wall, I started out with just having our psychologist to talk to, now I feel like I can talk to people who are experiencing or have experienced similar things as me. We've really made huge strides in terms of establishing a … parent's community.

Furthermore, their relationships to other parents provided them the opportunity to gain information about others' experiences with services and resources for their child. For example, Sara described the benefits of hearing others' experiences related to what has worked and what hasn't worked for her child, "You know you can talk to other parents, find out what's working for them, where they go for therapy, what they've tried, what things they've done, what schools are working for them or not working for them". Through sharing information, parents felt that they were building on the success of other parents.

With Professionals

Another way parents promoted success in their child over time was through relationships with a variety of professionals that were open and collaborative. Several parents described the role of professionals in their journey towards promoting success for their child. Heather spoke to the importance of feeling supported by the professionals in her child's life:

> Part of our journey has been the support systems we have had. And I can't speak for anyone else but I have, I have an amazing support system of professionals. And I think that is a benefit for any parent who has a child with autism is to have professionals that they can talk to without being dismissed, written off, or shut down when they want to try something out side of the box.

Parents also found success through developing relationships and connections with their child's professional team. As one mother stated, "the key to success is seeing yourself as an expert on your child while also seeing yourself as part of the team with the professionals that work with your child." The view that the parents were key members of the team was a recurrent comment.

Several parents also commented on the importance of collaborating and communicating with the school to promote success for their child. Kayla, for example, shared, "I check in with the school every day to see what is going on with school and what isn't. So at the beginning of the school year I let the teachers know about the social situations that he might have trouble with and keep me posted about what is going on with him." Similarly, Anna stressed the need to communicate daily and collaborate with her child's school team. She said,

> I am always in communication with his teachers; there is not a day that goes by where I don't have some sort of message from my teacher. We also do check in and check out. We have a team it is his teacher from last year, the principal is part of his team, and we have a family coordinator. I also talk to his school counselor because he is in a friendship group with the school counselor. They are always coming from a place of love and help, it's great.

In other words, through working with their child's school, parents were able to promote success for their child while their child was out of their home.

With Family and Friends

Parents also promoted success for their child by receiving support from their family and friends. Several parents described working together with their partner to promote success for their child, regardless of whether or not they were still together, as exemplified by Ashley: "I think it was really important that his dad and I were on the same page. Even though we aren't married anymore, we both want what is best for him. I am still very close with his dad." Outside of relationships with their partners, parents also spoke to the support they received from other family members. Kayla expressed, "My husband's mom was incredibly supportive, she wanted to learn everything and support me. And that was awesome, that was helpful."

Additionally, friends provided a source of support and connection for these parents. Sally spoke to the importance of having support from several people in her life including friends by expressing the following:

> There are all kinds of layers of people who support us. And I have a friend from work who I met a long time ago, and we have worked together for a long time. But if I must leave town for work, I am able to use the waiver to provide care for R but not my other children. So, it is a complicated mix, because I kind of have care, but I don't. … so having my friend to support me and take care of my children when I am out of town is crucial.

Advocating by Parent and Child

In addition to maintaining connection and relationships with others, parents ensured their child's success by advocating for them. Parents engaged in advocacy both individually and in collaboration with others. Further, they began to take on leadership roles as a way to help other parents who had children with autism. During the early stages of their life, several parents promoted success for their child by advocating for them. Laurie expressed the importance of acting to ensure her child was getting the right services, testing, and treatment. She said: "I was a huge advocate, to push to have her tested, and then pushed to whatever therapy she needed that was best for her and would make her successful."

Some parents reached out to others for support when advocating for their child. Maria expressed her satisfaction at having a local advocacy group member help her with a school meeting and with dealing with the unknowns of getting help for her child. Maria said,

> ... so the local advocacy group got involved, one of the advocates came into the meeting. And all I can say is she had my back, came into the meeting with me, helped me explains things as kind of an intermediary with me when I was upset and tried to help [the school] understand what we needed. And that kind of 'backup' is how I put it.

Over time, as their children developed, parents started empowering their child to stand up for themselves. Their roles as parents began to transform from advocates to teachers of self-advocacy skills to their children. Parents expressed how proud they were to see their children evolve as self-advocates. They noticed that once their child accepted their disability they were more able and willing to advocate for themselves. Laurie proudly stated:

> And then, all the sudden, it was just like, she became, one of her biggest advocates. ... first day of school in art class, she gets up in front of the class and they had to read a paper about something that they wanted the class to know and she get up there and said 'I'm Autistic.' And she tells me that and I am shocked because it's like where we came from, and it's like Wow! She has no qualms about telling people about it. I love that about her, because I think it makes her who she is.

Similarly, Christopher expressed his pride in their child not only standing up for himself but also participating in IEP planning meetings:

> We encouraged him to go talk to his teacher and speak up for himself. It was amazing. After the meeting we were so proud, he just opened up and talked more than we have ever heard before. He started to come to IEP meetings and advocate for what he wanted and needed too.

Once parents experienced success in advocating for their child and helping their child to advocate for themselves, they were motivated to reach out and assist other parents with this process. Several parents took on leadership or mentoring roles as a way to actively help other parents of children with autism. Susan, for example, stated, "I'm thinking [that] is one reason I wanted to become a leader and start this group is so our experiences can help the young kids coming up and the parents."

The desire to lead and be role models for other parents of children with autism was important for most of the participants in our study. Several parents described the need to feel connected and mentored by other parents who had experienced the lack of resources and professionals available in their rural state. They felt compelled to help others given their experiences and the empowerment they experienced when they were able to find and promote success in their own children.

Adapting to their New Reality

A final way parents viewed and promoted success for their child was through adapting to the new reality of having a child on the spectrum. Parents stated that raising a child with autism changed the way they interacted with their child over time. These adaptations occurred first through figuring out their internal emotions and reactions. Over time, parents began to accept that parenting a child with autism is different and hence success for their child is also differently manifested as seen in the quote by Jane below, the realization that even though what her child needed changed over time, the fact that he was healthy and home was a successful outcome.

> And (sighs) there's no success with autism, I gotta say this, I've never seen this, you just cope, there's coping you take every day one day at a time. You test medications if you want to do medications. Hmm … he's now

> on three different meds. He's now on three different meds. To try and because we are trying to find the right medicine that's not gonna do him any harm. But as he grows, what works is evolving and he's changing and (sighs) he's alive, he's healthy, he's at home. That's success in my mind (laughs). And things have gotten better.

Once they came from a place of acceptance and understanding, they developed greater emotional connections to their child. The majority of parents expressed the importance of being patient and flexible with their child. Christopher, for example, stated:

> ... What we have learned as parents is that you have to be super patient, pay attention to what they like, and help them pursue that and be open to help them pursing those things. Once we found out about his diagnosis, I was just not a very nice person before; he couldn't stop what I was telling him to stop doing. Once we realized maybe he couldn't help it, we are so much more patient with our other kids now ... it has all been about patience and understanding.

After recognizing their internal emotions and developing a deeper understanding of their child, parents took steps towards finding ways to manage and obtain resources that best met their child's individual needs. Parents in this study were very involved with their children's lives. They had high expectations, but at the same time, got emotional when their child accomplished even a relatively "small" or "normal" task. For example, when their child was able to communicate his or her feelings or need for space. Jennifer expressed her adaptation process which led her to accept her son the way he was as seen in her quote below:

> We never turned away; it was all about what do I need to do to make him feel comfortable, safe, and happy. He is very high functioning because his obsessions are his obsessions [and] are those for life, and what we do is that we just go with it and just accept okay that's who he is. We try to keep his life as full as possible.

As parents adapted to their new reality, their understanding of their child changed. Some parents described having different or lower expectations at the time of the autism diagnosis and then experiencing changes in their expectations as the child went through different phases and experiences. For example, one mom of a teenager on the spectrum was most grateful and pleasantly surprised that her daughter was driving at 16 years of age like any other teenager. It still took preparation and planning for her to do that but it was such a relief to not have to get her child to and from college for very visit home.

For several parents, adapting to their new reality meant educating themselves and become familiar with the resources available to them. Parents took initiative to research, read, and educate themselves on various treatment and intervention options. Finally, parents adapted to their new reality through attending to their self-care needs. Parenting a child with ASD can be stressful and demanding. Parents expressed the importance of self-care, using respite when needed, and attending to the stressors in their lives. Brandy, for example spoke to the importance of attending to her own needs and pursuing ways to take care of herself:

> One of [the personal strategies I use to take care of myself] is that I love animals. So, when we lived in the country and we had little horses and things and that was my kind of stress reliever. I like to take care of wild baby animals. I try to walk and try to keep active that's important too, I think. And try to eat healthy. I can tell when I don't eat healthy, things are harder to cope with.

Brandy's example highlights the utilization of unique rural resources, to help her be more resilient, to be able to take care of her child. Jennifer also shared the importance of using respite care and the gratitude for having a Medicaid waiver to pay for respite care. She said,

> Respite care helps our family. We have used a lot of our waiver funds for this. I am older and I have grandkids and sometimes I need to take time for myself with just them. So, for me, the respite care is there so we can continue that part of our family life ... And I think that keeps our family in balance.

Overall, parents found success by adapting to their new reality through patience, flexibility, attending to their self-care needs, and through educating themselves about resources and interventions in their rural environment.

Discussion

This study found that parents of children in rural settings who have children with autism have many of the same desires for their child's life, including goals for community inclusion, employment, and wellbeing. However, due to the limited resources in rural communities, these parents have had to conceptualize success more broadly and rely on resources beyond the healthcare system. In the AI framework, success takes a flexible approach in which the parent must work with a variety of systems and find resources that may not be consistent with clinical guidelines, but may be in line with the outcomes that they value as the most successful.

Our study addresses systematic information on what works for families with children with autism, specifically by providing perspectives on success for parents raising their children with autism in a very rural/frontier community (Wyoming). In particular, success was dependent on the context of the child, situated within his or her family and community. Parents described success by their child developing skills such as independence and self-regulation. These actions were specific to the strengths of their children (e.g., for one child, doing homework might be an important skill while for another doing chores around the house was counted as a successful outcome). Outcomes per child included ability to regulate emotions and communication and being independent (relative to other abilities). Social supports and environment was described by parents in terms of the social connections and adapting to their new reality of raising and understanding their child with autism. These supports parents can be described across three levels: (1) Individual-level supports were emotional- and relationship-based including respite care and self-care; (2) Society/environment level included financial support from family and spouse, e.g., ability of mom to quit job or work part time to care for her child with autism; and (3) community-level supports included all kinds of support from community members who were both trained (health professionals, school personnel) and untrained (parent support groups).

Findings from this study are consistent with previous findings that report increased parenting-related stress for those living in rural communities (Thomas et al. 2007). Previous studies have shown that despite geographic location, parenting a child with autism is also associated with increased stress (Caicedo 2014; Dykens et al. 2014; Findler et al. 2016; Miodrag et al. 2015), as well as decreased physical and mental health (Caicedo 2014; Cantwell et al. 2014; Dykens et al. 2014; Gallagher and Whiteley 2013; Miodrag et al. 2015). Some parents of children with autism have described their experience as a "balancing act," in which they are constantly attempting to create balance for their families, their child/ren, and themselves (Robinson et al. 2015). More importantly, beyond increased stress, parents of children with autism in our study described wanting similar outcomes for their child as parents of neurotypical children do (e.g., skills, social connection, purpose in life). This is remarkable because rather than choosing to define success differently for their child based on their child's abilities, these parents maintained similar notions of success despite their child's disability. However, the steps necessary to achieve these outcomes were different for children with autism, and their parents needed to employ different tactics to promote success. Parents also appeared to be more conscious of developmental milestones that parents of typically functioning children may take for granted (such as talking and making friends).

Overall, specific to a rural state location, the strategies by parents in our study did not differ greatly from any other parent of child with ASD wanting to have successful outcomes. However, as mentioned above, the processes to obtain that success differed in a rural community as seen through the "developing skills" and "adapting to new reality" themes in the results. Also, in a small town, the protective factor of others knowing their child created additional support for parents and helped them build long-term and close relationships with the community members. Importance was placed on developing advocacy skills by parents and this could be a part of their process to develop advanced supports for themselves and their child. The theme "advocating by parents and child" led to the emerging significance of peer mentoring and online support groups. Such groups could provide opportunities to promote public health or community program elements for success in a rural state.

While parents in our study did not have easy access to healthcare specialists, they believed the clinical support that they had was critical for their child's success. This was particularly relevant for helping with emotional regulation and behavioral interventions; however, parents seemed to consider services more broadly. Education and non-professional community supports including schools and after-school care centers were important and provided many of the same benefits as clinical settings (e.g., social skills). Further, families in the community who had children with autism or another developmental disability provided connections to parents in our study that were most highly valued since was sympathetic of their needs.

While not the only form of service for parents in successfully raising their child with autism, traditional clinical care still remains extremely important. Given the persistent healthcare shortages in rural communities, there is tremendous opportunity to increase capacity to meet these needs. Given that integrating their child into the community and adapting to their family was equally important to parents as their child reducing his/her problem behaviors or gaining academic skills, existing clinical practice may be able to include goals that meet outcomes as desired by the families and explore ways to align with unique protective factors seen in some communities. For instance, high degree of community support/inclusion allowed children to "be themselves" more. Such inclusion was the type of ultimate success parents envisioned for their child. Rural inclusion was seen through community participation, education, employment, and many other areas of community life that are not always supported elsewhere. There is already buy in and work towards such inclusion and public health programs that support this direction would need to be explored in the future. Ultimately, looking into breaking down silos of support and providing natural supports is suggested to foster success for families raising children with autism in rural areas as well as to further our understanding on how to make such interventions applicable to other settings.

Limitations and Future Research

One study limitation was the small sample size for this study; typically, AI interviews would include a few more for a minimum sample of 25. However, relative homogeneity of sample helped us achieve saturation earlier than anticipated. In addition, participant bias due to self-selection into this study might have been another limitation wherein more involved or even more successful parents might have answered the call for interview. However, we had a reasonable range of responses from our participants suggesting we did not only capture a limited segment of the population. In addition, while the study intent was to interview parents of children with autism, mostly mothers were interviewed in this study excepting one father and two couples. The results of this study need to be interpreted with this context/limitation in mind. Lastly, while the study sample was not very diverse in race and ethnicity, it was very reflective of the diversity in the state.

A future study could involve interviewing children or adults with autism regarding success and processes and outcomes that led to the successes with their ASD management. Additionally, comparing success for parents in urban versus rural locations and outcomes for their child with autism would be an important aspect to learn. Conducting similar success-based interviews with parents of children with other developmental disabilities might give a direction for future interventions to improve outcomes for children in a rural location.

Common assumptions of health care systems management may not apply in rural communities in their originally intended way. Clinical services are still desperately needed; however, the realities of raising a child with autism in a rural environment mean that other sources of support may be more available and may support the outcomes that are meaningful to the families. If true, this suggests that healthcare policy as it pertains to rural communities could serve these families better through the use of non-clinical- or community-level supports to help families achieve the successful outcomes that matter most to them.

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Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no competing interests.

Ethics Statement The University of Wyoming Institutional Review Board reviewed and approved this human subjects study.

Informed Consent Statement Informed consent was obtained from each parent participant in this study before data collection—interviews were conducted.

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