

## Research Article

# Parental Perspectives on Children with Autism Spectrum Disorder and Developmental Disability

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## Abstract

The purpose of this study was to investigate and analyze perspectives formed in raising children with Autism Spectrum Disorders (ASD) and Developmental Disabilities (DD). The development of behavior, temperament, and communication abilities within the context of family needs and issues served as the primary objective. This qualitative, descriptive, phenomenological study identified a broad range of challenges and family stressors. In response, parents focused on preparing children to function at optimal levels. Healthcare therapists are advised to support this persistent devotion to the improvement of practical expertise through the application of affirmative and substantiated practices. A health equity-based approach will aid in the development of shared goals. The commitment and sacrifice of these parents provides drive and reinforcement for the improvement of current practices and impetus in the search for better ways to help their children.

## ABBREVIATIONS

ASD: Autism spectrum disorder; DD: Developmental Disabilities

## INTRODUCTION

This study was begun to follow the formation of parental fields-of-view when coping with children who have Autism Spectrum Disorders (ASD) and Developmental Disabilities (DD). The development of behavior, temperament and social communication within the context of family issues and needs served as the vantage point for this investigation. The researchers were also interested in finding indicative parental narratives that could be used to provide recommendations for healthcare therapists.

ASD is a pervasive neurodevelopmental disorder characterized by atypical sociability, impaired social communication skills, repetitive behaviors, restricted and repetitive interests or activities and unusual sensory responses [1]. Temperament has been recognized as contributing to the behavior of children with ASD [2]. Temperament can be defined as the basic foundation of personality and includes characteristics such as energy level, emotional responsiveness, demeanor, mood, behavioral inhibition, and willingness to explore. Synonyms for temperament include inclination, nature, outlook, tendency, mentality, personality and disposition [3]. Maladaptive behaviors of children with ASD may lead to family stress. Families are affected by the child with ASD as are siblings who can be impacted in both positive and negative ways [4].

Research is needed to develop a comprehensive understanding of the contemporary experience of raising children with ASD and DD. Its findings may be used to inform community healthcare providers of the mindset and perception of the current generation of parents. Overall strategies as well as specific tactics can then be developed to provide services that can be both adaptive and effective.

## METHODS

This was a qualitative, descriptive, phenomenological study. Audio taped interviews were conducted with parents raising children with ASD and DD, in person and by telephone from November 2018 to May 2019. Parent volunteers were recruited from a college-sponsored community music therapy program where their children came for weekly therapy. Parents signed college institutional review board approved consent. The parents chose a pseudonym for themselves and their children in order to assure confidentiality. They were asked to describe their parenting experiences and focus on the child's temperament, behavior, social communication, and family stressors. Advice for health care therapists was solicited. Colaizzi's analytical approach [5] was implemented in data analysis. This procedure required identification of significant statements, meanings, and themes.

## RESULTS

## Demographics

18 parents reported on 20 children in this study. One parent discussed his three autistic children. 14 of the respondents were

mothers and 3 were fathers. One was an aunt and the full-time caregiver. The children included 16 males and 4 females, aged 3 to 21 years. The parents provided the following unverified diagnoses. 17 were described as having autism. One of those identified Asperger's as the earliest diagnosis given. The others had Jacobsen's, Rett and Down syndromes with autistic features. Their time spent in music therapy ranged from 4 months to 14 years. Family composition included 17 situations in which both parents resided in the home and 1 with a single-parent. Eighteen of the children had siblings while two were only children. Two of the children had a twin and one was a triplet (Table 1).

**Themes**

Three thematic content areas emerged from parental data. These included assessment of a child's temperament, behavior, and communication within the context of parenting styles (My Child); family issues, stressors, and needs as impacting delivery of help to the child (Our Family), and parents' interactions with therapists (Advice for All Types of Therapists).

**Themes about My Child**

Each parent was asked to describe their child's temperament, disposition, or personality as they best understood it, behavior and social communication skills. They were also asked to relate their experiences as parents in regard to these issues.

**Personality/disposition/temperament:** Adjectives used to describe the children were generally quite positive. Children were characterized as easygoing, compliant, good-natured, flexible, happy, sweet, delightful, energetic, affectionate, kind, loving, and calm. Parents reported many sociable traits such as "he even likes to be hugged." Rob, a 7-year-old is "steady and consistent" and Bear, a 7-year-old is "loving, spunky, cute, and full of energy." The parents seemed to really enjoy discussing these traits and described wonderfully behaved children. It was as if they were not describing a child with any problems or ASD. Their children were ideal.

**Challenging behavior:** As the interview progressed, the parents related challenging behaviors that reoccurred periodically. They described extended crying, hysterical screaming, hitting, poking, inappropriately touching others, having meltdowns, anxious activity, and acting in ways that were dangerous to themselves or annoying to others. Some spoke of furniture being destroyed and self-inflicted injuries or even injuring others when he/she was in an unstoppable rage. The consensus was that the "bad" behavior was not the real child's personality. Allison was pleased to offer that her 9-year-old son no longer bites but still pokes at others and "gets up very close in

peoples' personal space." Jack, an 11-year-old only child, presses his forehead against others but rarely slaps or hits. While Mary, a 15-year-old was described as silly and talkative. However, she can go into a rage and throw things, scream and yell when upset. James, a 5-year-old who is normally "happy-go-lucky" can be easily frustrated and have unpredictable episodes where he "hits whoever or whatever is around." Such episodes could occur "every half-hour throughout the day but fortunately last less than a minute." David justified his son's behavior as "really just mischievous."

**He can't help it when he gets that way; we can manage:**

The parents excused challenging behavior in rationalizing that the child could not help it and that the family could manage. The main idea was that it was not the child's fault. Eileen said that the family must "just accept" their daughter's behaviors. Beatrice explained that her 8-year-old son bangs on the furniture but at least he no longer bangs his head. Although tapping and drumming on furniture can be upsetting to others, she said, "I don't love that he destroys furniture but I see it as something that he needs to do ... all day long." Taddy said her 16-year-old son has not bitten anyone in a long time but still pinches and squeezes. She indicated he had poor impulse control and is like "a bull in a china shop." His parents described him as playful but cannot help himself when he throws his toys and the family must just get out of the way. Maria explained that her son's behavior was related to his inability to communicate, so it was understandable that he was really just frustrated. Allison excused most of her son's behavior as just being age-related like other typical children. Elysa felt her teenaged daughter's behavior was excusable as it must be hormonal. Rob, a 7-year-old boy can "bite his clothes, clench his fists and progress to a full meltdown." His behaviors were attributed to broken routines and loud noises. It was all understandable to his mom as he is fine if he has consistency.

**Treasured talents:** Parents were happy to point out descriptions of "good behavior" and a variety of talents that balanced out the "bad behavior." George, the father of 3 sons with autism, indicated that the boys are challenging and can become physically reckless, they are also able to entertain themselves using television, videos and home activities. One son has a "photographic memory and is a great artist and skilled with geography. However, Dad lamented that he whines continuously until he gets his way." Christine indicated her 11-year-old son enjoyed dancing, jumping up and down and singing with music videos. Small progresses in activities of daily living were described as positive achievements and treasured talents. Learning to be active on playground or yard toys or being able to take a trip to the movies or a restaurant could become repetitive skills the parents fondly told of.

**Table 1:** Participant Demographics.

<b>Number</b>	18 Parents, 20 children * 1 parent had 3 children
<b>Parent Role</b>	14 Mothers, 3 Fathers, 1 Aunt caregiver
<b>Child Gender</b>	16 Male, 4 Female
<b>Diagnosis</b>	17 Autism, 1 Down's Syndrome, 1 Rhett Syndrome, 1 Jacobson Syndrome
<b>Family Composition</b>	17 Both parents in the home, 1 Single parent in the home 18 had siblings, 2 were only children 2 had a twin, 1 was a triplet

**Social communication:** Slow progress in social communication was common. Most of the children used a few words or a communication device to express needs. Some could speak in phrases while a few used full sentences. Expressive and receptive language deficits were thought to be a major source of frustration for the child. Parents considered deficits to be a main source of inappropriate behavior. They also attempted to anticipate needs in order to avert frustration. Teresa reported that she supplies missing descriptors to situations for her 6-year-old son in order to preclude possible anxiety. Annie said that although her 6-year-old son can have an “up to a 40-minute meltdown”, using his communication board can help him calm down (communication boards or communication devices were credited with improving expression and lowering frustration for many of the children).

Social skills had improved as communication had slowly developed. Parents described their children as socially appropriate (except during behavioral episodes). They could interact in positive ways with family, school, or therapists. All the children were credited with laughing accordingly or smiling responsively.

**My child:** A principal finding was the child’s developing role in the life of a parent. The child became a parent’s “whole life” and a “full-time job”, as Maria said of her 5-year-old son. She has taken him “everywhere” to broaden his experiences. David indicated that his 3-year-old son is his “whole future... my family, loves him dearly.” The father takes on additional work in order to provide for his son’s supplementary activities and therapies.

The parents may be considered, without exception, as devoted, resolute, and inexhaustible in their commitment to their children. They outlined a very supportive, caring, and involved parenting style. They juggled their home and work life in order to be always present for the child. As Alfred said, “It’s not an easy thing to do, it’s a grind, it’s not for everyone, it’s a demanding job to be the caregiver. It’s not a good life but it’s a noble deed.” Bethany said, “we are going to do everything we can... we are going to be successful and do whatever we need to do for her” (her 7-year-old daughter).

Children with ASD and DD require unusual time, attention, supervision, guidance and special procedures. The study parents provided for the children without reservation. They sacrificed their own personal needs so as to provide a well-balanced home for their spouses and other siblings in the home. They were determined to become consummate parents despite any costs to themselves (Table 2. Themes about our Child).

**Themes about our Family:** Some family homes had been adapted to accommodate for a child’s special needs. Modifications included locks on all doors to prevent escape and on cabinets to prevent unsupervised access. Picture books, toys, musical instruments, and climbing equipment were provided. Families went on outings and special vacations. Such adventures were not easily undertaken and required a great deal of planning to assure safety as well as enrichment and enjoyment. Even a simple local day trip could be complicated by the child’s behavior or an upsetting experience.

**Working together-creative efforts:** Parents and siblings worked together to help provide for the child’s needs. Teamwork was a commonly used word to describe the family functioning. They looked for creative ways to best help the child function. David said, “we are a team and we help each other out and get through any difficulties.” Parents were always on “the alert.” They tried to anticipate and avert an upsetting experience for the child. Empathy had been forged for the child’s peaks and valleys, pain and discomfort. Family members tried to prevent it or at least catch up with it. A common precaution when taking the child on an outing was for the parents to sit near an exit in preparation for potential situational crises. Behaviors ranged from a few tears or sadness to a “full blown meltdown” especially when out. Parents responded to such experiences by trying to avoid those places proven to be upsetting. They might bring special snacks, stimulating objects or small toys as distractions or calming resources. They also tried to “talk the child down” when upset. Although Paddy’s home has child locks everywhere, he still needs constant observation to prevent unexpected exits. As he eats inappropriately, he can choke on his food. His family must take turns keeping watch over him at meals. Five-year-old James with autism lives with his parents and 8-year-old brother. The mother credited the family with the ability to work as a team with James. She felt that the family is on the “right path” and said “if something doesn’t work, be flexible and think of it in a different way”. James’s eight-year-old brother knows how to deal with upsetting behaviors by “ignoring it” or saying “hands down, no hit”.

**Family goal-to be the best that he can be:** Although development was defined as being quite slow, even very small improvements were seen as monumental. One mother said, these children are “working extra hard at things” or even “twice as hard as us....they don’t have the same choices that we adults do.” Maria’s approach was that “we are just trying to fix our children and make them as high functioning and independent as they can be.” Alfred indicated that he and his wife continue to try to help

**Table 2:** Themes about My Child.

Theme	Examples
Personality/disposition/temperament	Happy, calm, loving, easygoing, sweet, delightful
Challenging behavior	Anxious, crying, screaming, hitting, annoying, having meltdowns
He just can’t help it when he gets that way	It’s not his fault: we can ignore or manage the challenging behavior
Treasured talents	Music, art, dance, gaming, daily functioning progress
Social communication	Frustrating ability, making slow but definite progress
My child	He’s my whole life, my full-time job

their 21-one-year old son Nicholas self-actuate and become more independent. Although he prefers to be alone, he is brought to programs and therapies every day. Anthony, a 6-year-old boy's mother said "we love him so much and know he is capable of such amazing things...we want to give him all these opportunities... and have a happy, successful, and productive life." They "celebrate" everything about him. He is making "huge progress with every little achievement." Incremental accomplishments "for my son might have taken him a very long time. Learning to zipper is a small thing for some parents but we were jumping up and down and celebrating it."

The parents expressed a common dream. They wanted their children to realize their fullest potential and "be all that he can become." This may be only learning to speak in a few words or phrases, or to be able to sit and interact calmly with friends and families in a restaurant.

**Concerns over the child's future:** Worries for a child's future included uncertain appraisals of the possibilities. As one mother said, "who will be there for him when we are gone?" Some parents spoke of a plan for the child's living arrangements. Alfred said "Our house will go to him (their son) and we will move out of the house and it will become like a group home for him. It will go into a trust. There's a lot of legal paperwork for this." Another mother has researched group homes and will try one now that her daughter is older. Allison's son is still only 9-years-old but she keeps "worrying about the future and who will take care of him" when the parents cannot. Paddy's mother worries a lot about his future now that he is 16. He is non-verbal and she is most concerned that he cannot communicate his feelings. Eileen is concerned for her 7-year-old daughter's future and set up a special needs trust.

**Family stress and needs:** Family stress ranged from a reported low to an "exhaustively" high level. Each had a different example of stress on themselves or family members. One mother said "I can take it but my husband found counseling to be helpful." Maria said there is constant stress. She "feels helpless and like a failure as a parent" when she cannot figure out why her 5-year-old son Christopher is crying. "It's heartbreaking." She says Christopher's 7-year old brother was sarcastically asked at school if Christopher was "stupid." Siblings were described as full participants in helping but parents also worried about the experience of growing up in such a family. Stress could also be related to the child's limited basic skills. At 16, Paddy is still not toilet trained. His mother said this is quite stressful and it limits family outings. In describing family stress, David indicated that he and his wife feel "afraid" for their 3-year-old son's situation. Eileen feels increased stress whenever her daughter is hospitalized due to her Rhetts syndrome. She also wishes that she could have more time to spend with her other children. She has found help through support groups and recommends that other parents do the same. Bethany said she worries a lot about her 7-year-old daughter with Jacobson's syndrome and also wishes the family could have "more quality time together." Maria wished that "supportive services were not so difficult to obtain with less paperwork and assessments." Zelda forecast a decrease in stress level as her son develops better communication skills and she attends counseling. One mother said that "everything is hard...it's tough, my kid still wears diapers and he's nine. I feel like people

need to understand that it's not a terrible thing. I wish my son didn't have to go through the struggles he has to go through. I try not to complain about it...but when I am having a bad day, it's because I just cleaned (his feces) off the floor that my nine-year-old son took out of his diaper and spread all over". Then she added, "I'm not just a lazy mother who doesn't want to potty train her kid" She felt that parents should not be sorry for her, but they should be grateful for their own neurotypical children. Respite care would be a welcomed alternative to babysitters who were rarely an available option. Another mother related that play dates for siblings can be difficult due to her son's behavior (Table 3. Themes about our Family).

**BENEFITS OF MUSIC THERAPY**

These parents had been bringing their children to weekly music therapy sessions during the school year. Music therapy was found to be a source of excitement, enjoyment, and the building of confidence as well as becoming a positive emotional outlet. It was described as producing calming, relaxing, grounding, and spirit-elevating effects. The children had learned to take turns in conversations, sing, to increase their vocabularies, to expand their social and communication skills, to follow instructions and to use song as a means of communication. The parents' confidence in music therapy helped them to continue to bring their children to sessions over a period ranging from months to many years. Parents were quite pleased with music therapy and the interactions with their therapists. The therapists' "personal touch" during the brief weekly parent/therapist post-session discussions was appreciated. The value of regularly scheduled conferences was also acknowledged.

**ADVICE FOR ALL TYPES OF THERAPISTS**

The parents were asked to consider any general advice they might offer to a therapist of all specialty types, not just music therapists (See Table 4.). In addition to music therapy, many of the children had home therapists or therapy provided by a school system for occupational, physical, speech, and horseback-riding therapy. While some therapists received parental praise, some were discontinued when family expectations were not met. A general theme expressed was that therapists should not make assumptions about the child, parents, or treatment options.

**He's the most important person in my life**

One reminder was that "he's still my son and he's still the most important person in my life." The parents were highly devoted. There was always a focus on the child. One described

**Table 3:** Themes about our Family.

Themes	Examples
<b>Working together-creative efforts</b>	Teamwork, avert episodes, find creative ways to help the child function
<b>Family goal: to be the best he can be</b>	Helping the child reach his fullest potential
<b>Concern over the child's future</b>	Who will be there for him when we are gone
<b>Family stress and needs</b>	Generalized feelings of stress, concern over sibling adjustment. Need for respite care, easier access to programs, to be able to spend more time as a family

**Table 4:** Advice for All Types of Therapists.

Themes	Examples
<b>He's the most important person in my life</b>	Always in my thoughts, need to be involved in everything including therapy
<b>Appreciate parent's unique expertise &amp; protective devotion</b>	Parents have valuable knowledge of the child and the condition
<b>Sharing of goals, expectations &amp; strategies</b>	Understand what the family wants
<b>Interact with parents on a personal level</b>	Get to know the family & what they are dealing with
<b>Therapeutic approach</b>	Flexible, adaptable, patient, positive, enthusiastic, treat child with respect & as unique

the child as being in her thoughts "at all times" and that it was "all consuming to be his mother." She needed to be involved in everything including therapy. Another observed that it was "easy for them (therapists) to give advice but at the end of the day they are our children, it's our life." One mother had been advised to turn away from her son when he cries. She protested that "how can I walk away when he is hysterical crying?" Another testified that "there's definitely been some therapists that have not lasted with us. You have to find the right ones to fit your family and fit your goals."

### **Appreciate the parents' unique expertise and protective devotion**

Parents felt they have valuable knowledge of how their child functions, their idiosyncrasies, and what sets the child off into a behavioral. They also have spent years learning about the child's condition and may be well-versed. The parents wanted therapists to appreciate their role in the therapeutic relationship and acknowledge their expertise and protective devotion to their child. One asked her therapists to "remember, they are children and we are the parents."

### **Sharing goals, expectations and strategies**

Parents emphasized the need for ongoing individual assessments with frequent debriefing. Some felt uninvolved and not welcome by a therapist. Others felt the need to communicate their wishes but did not see enough opportunities to do this. Communication should include a sharing of goals, expectations, and strategies. There was a need for the therapist to identify what the parent wanted to occur during therapy and the final outcome that they hoped for.

### **Interact with the parents on a more personal level:**

There was a general desire for a more interactive and personal touch. One parent said, "a therapist becomes a part of the child's and parent's lives." They wanted a therapist to "get to know the family and what they are dealing with." Another parent saw the need to help therapists "feel comfortable" with the child and the family. One also cautioned that "you don't want them to burn out." Those that had long-term relationships with a therapist were pleased. One father said; "its hard to break a new therapist in...it takes a long time for us all to get used to each other."

### **Therapeutic approach**

One mother reasoned that "strategies need to be "flexible and adaptable with a wide range as no child is the same." Another complained that therapists should "increase their awareness of the autism spectrum" and indicated that rules and timeouts weren't effective for her child. Another comment was that children should be treated as "unique individuals and not be treated the same." One mother emphasized that "if something isn't working, the professionals need to admit to that and not waste precious resources." Parents wanted therapists to be patient, positive, enthusiastic, empathetic, and to demonstrate care and respect as one would for any "typical child, without labels or generalizations" as well as to keep an "open mind."

### **CONCLUSION/IMPLICATIONS**

Themes drawn from the data highlight related concepts that would benefit further study.

This study illustrates parental experiences with ASD and DD. Community healthcare providers and nursing professionals should be aware of parental and family concerns. Parents desire that recognition of their child's personality and behavior be clearly included in the formation of therapy strategies. These parents persevered despite obstacles and with great sacrifice toward the goal of the most beneficial outcomes. It is possible that the construct of goodness of fit [6] was a presiding factor and might help us understand these parents who persevered in the face of challenging behavior. All the parents seemed well matched to their charges. Their resilience and hope epitomize the principles of health equity both in theory and practice. Parental frames of reference influence potential resolution of personal, family, and social problems common to ASD and DD. Healthcare professionals are advised to appreciate such devotion and hard-earned expertise. Enhanced communication and the maintenance of a reliably positive and enthusiastic attitude should be primary. A health equity-based approach would aid in the development of shared goals between parents and therapists. The psychological and physical well-being of this segment of a community depends on continued study as was identified by Safe, Joosten and Moleneux [7]. They found that parents, especially mothers, felt the need to accept their child for who they were but also wished for their growth and development. It is also probable that parents may not always be as well matched as those in this study and experience negative co-parenting relationships. Family stress due to ASD may affect the parents' relationships with each other and that with their other children [8]. Negative co-parenting was not described by the participants in the present study who emphasized a cohesive approach.

### **LIMITATIONS**

This study had a small participant number of 18 who were mostly boys. The qualitative results cannot be generalized and should be viewed as narrative examples of a group experiencing common problems associated with ASD and DD. The parents were volunteers taken from a larger quantitative study of parents bringing their children to a music therapy program. The nurse

researchers were not associated with music therapy. Efforts were made to assure confidentiality without any names shared. It is hoped that the parent's general praise of music therapy was objective and not influenced in any way.

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