Autism Spectrum Disorders and Positive Familial Effects

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Abstract

Autism Spectrum Disorders (ASD) have been found to significantly impact familial structures and outcomes in various studies. The majority of the impact, however, has been primarily negative; effects like increased stress, marital discontentment, and stigmatization are commonly expressed by families. In this study data from a questionnaire, interview, and picture presentations were analyzed and triangulated to identify the positive familial effects of having a child or sibling with ASD. Parents and siblings shared that having a child or sibling with ASD has bettered their life through learning to enjoy the identity of the individual with ASD, through personal growth, and thorough positive environmental differences. These findings encourage further research into how individuals with ASD positively influence families and society.

Keywords: ASD, Positive Perceptions, Positive Effects, Family Systems, ASD Siblings
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Overview

As one of the most increasingly prevalent developmental disorders, autism spectrum disorder (ASD) serves as a label for a range of atypical behaviors and developmental delays. According to the Center for Disease Control, about one in fifty-nine children were diagnosed with an autism spectrum disorder in 2014 (Baio et al, 2018). Usually diagnosed from ages two to five, ASD is a childhood disorder that has an unknown cause, no established prevention or intervention method, and no cure (Parritz & Troy, 2018). ASD drastically affects how “one communicates and experiences the world,” often observable in language deficiencies, social difficulties, repetitive behaviors, and restricted interests (Autism spectrum disorder, 2017, p.1). As a complex disorder that is affected by genetics, pre-natal environment, neurobiology, and interacting bodily systems, ASD is known for being “heterogeneous [and] impacting each individual differently” (Boutot, 2017, p. 20). The symptoms of ASD can vary in manifestation and can change as the individual matures, making consistent intervention and progress difficult.

With the increased prevalence of ASD over the past decades and the significant impact on daily life associated with the disorder, families with children who have been diagnosed with ASD face a unique challenge unlike nonaffected families. Language deficiencies change familial communication, social difficulties affect familial understanding, and behaviors such as repetitive actions or restricted interests impact familial functioning. While significant amounts of research regarding ASD causes, interventions, and behaviors has been conducted, there is much left unexplored concerning how ASD positively impacts individuals within family units.
Literature

The majority of literature that addresses the influences on the family of having a child/sibling with ASD focused on how the family is negatively affected. Much of the literature also does not analyze ASD specifically, but instead looks at developmental disabilities as a whole in their effects on the family unit. Using keywords such as ASD, quality of life, autism, siblings, family, and parental perceptions, various studies were found to be pertinent to the discussion of how a child with ASD affects individual members and the family as a whole.

In a systematic analysis of parents’ reports of their life with a child with ASD, Myers, Mackintosh, and Goin-Kochel (2009) found that, of the parental responses, 48% presented a negative tone throughout, 39% had a mixed tone of both negative and positive statements, 10% were positive in tone, and 3% were marked as unclear. This data shows a marked inclination toward the negative impacts of ASD on the family, leading to the assumption that parents identify more negative than positive effects of ASD. This can be attributed to the finding that families affected by ASD report higher stress and lower quality of life than families with non-ASD members, whether they be neurotypical (Baker-Ericzén, Brookman-Frazee, & Stahmer, 2005; Estes et al., 2009; Vasilopoulou & Nisbet, 2016) or with other developmental disabilities (Dabrowska & Pisula, 2010; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). The following analysis utilizes the categories of stress laid out in Seligman and Darling’s (2007) book, Ordinary Families, Special Children, but extends the structure to include the reported positive aspects of life with an individual with ASD.

Intellectual Effects

Intellectual stresses as seen in the shock of a diagnosis can be a traumatic experience for
families and is described with language like “a thunderbolt” or “shattered dreams” (Oprea & Stan, 2012, p. 3). The battle of intellectual stress is related to the family’s ability to comprehend the nature of the disability and gather the information needed to continue. Through the search for an accurate diagnosis, intervention or etiology, parents can receive many different opinions or technical information, possibly leading to unproven methods of treatment (Seligman & Darling, 2007). In one study, intellectual stress was the highest reported type of stress for family members of an individual with intellectual disability (Simson, 2013). Parental understanding of their child seems to increase as familiarity with their child’s diagnosis increases, as evidenced primarily through qualitative studies (Welteroth, 2001; Cascio, 2012). A seemingly common coping mechanism of intellectual stress is the tendency of parents to separate their child from the disorder, seeking who their child may have been without ASD (Hines, Balandin, & Togher, 2011).

**Instrumental Effects**

The instrumental stresses of families affected by ASD are of a practical nature, such as care-giving burdens or financial impact. The care-giving responsibility of parents for their child with ASD is a primary cause of stress. Factors that lead to care-giving related stress include the severity of the child’s ASD-related behaviors (Estes et al., 2009; Vasilopoulou & Nisbet, 2016; Wayment & Brookshire, 2017; Myers et al., 2009) and the prolonged/constant nature of the care-giving (Dardas & Ahmad, 2014; Green, 2007). Caregivers, primarily parents, are likely to ignore their own health needs, leading to physical exhaustion or lack of sleep (Dardas & Ahmad, 2014; Vasilopoulou & Nisbet, 2016). The monetary impact of raising a child with a developmental disability is one of the most commonly reported concerns (Dardas & Ahmad, 2014; Green,
2007). Within the population of families affected by disability, quality of life and income are often positively correlated due to expensive interventions and medications (Vasilopoulou & Nisbet, 2016). The fact that many mothers struggle to maintain employment when their child has a severe disability also adds to the cycle (Vasilopoulou & Nisbet, 2016). The only instrumental positive theme identified was the development of skills or passion for one’s occupation (Hastings & Taunt, 2002).

**Emotional Effects**

Another important aspect of the stress put on families affected by ASD is the emotional stress of diagnosis and life with the affected individuals. The grief associated with receiving any diagnosis is understandable (Simson, 2013), but, while traumatic, dissipates over time and as the parent adjusts (Green, 2007). The grief related to ASD diagnosis, though, is unique among developmental disabilities as it is delayed and can lead to extended periods of distress and hopelessness (Wayment & Brookshire, 2017). Fathers have described their child’s diagnosis as “comparable to the loss of a typically developing child” (Burrell, Ives, & Unwin, 2017, p.1135).

In her 1987 poem, Emily Perl Kingsley described her experience of having a child with special needs through the metaphor of eagerly planning for a trip to Italy, only to arrive in Holland. Kingsley (1987) makes special note that while the grief for Italy is significant, Holland, too, has many beautiful things to offer. Mothers in particular experience increased levels of depression (Dardas & Ahmad, 2014) and psychological distress (Estes et al., 2009). One significant and common predictor of this distress is identity ambiguity, defined as an unhealthy inability to separate one’s identity from their child’s disability (Wayment & Brookshire, 2017). No studies were found that relate this concept to sibling relationships.
Furthermore, the emotional complexities of having and raising a child with disabilities is explained as “the embrace of the paradox [of] loving the child as he or she was and wanting to erase the disability” (Larson, 1998, p. 875). This conflict is expressed in many other studies and despite the complications, many parents shared feelings of pride (Green, 2007). One of the less common but significant emotional effects is that in many anecdotal articles, parents with children with ASD call for acceptance of their child instead of wishing for their child to be neurotypical (Welteroth, 2001). This perspective is consistent with the neurodiversity movement, which celebrates the strengths of ASD (Baron-Cohen, 2019) and appeals to mothers’ understanding of their child’s behaviors (Cascio, 2012). This kind of pride is seen primarily in qualitative research; one parent even “describe ways in which autism may have contributed to valued aspects of [her son’s] personality” (Hines et al., 2011, p. 20).

**Interpersonal Effects**

Interpersonal stress is another commonly reported effect of having a child or sibling with ASD. In a study on the predictors of outcomes for parents of individuals with ASD, Dunn et al. (2001) found that the most powerful coping mechanisms parents used led to increased social isolation. A variety of factors led to these parents’ understanding that they are not accepted in society. Often feeling marginalized or judged by society, parents believe that the stigma of having a child with a disability is widespread (Oprea & Stan, 2012; Welteroth, 2001). Parents in a qualitative study “revealed belief that their son’s or daughter’s challenging behaviors reflected on them as parents” (Hines et al., 2011, p.21). Siblings also reported interpersonal stress with themes of loneliness, depression, and other socially inhibitory feelings (McNamara, 2012). The opinions and suggestions of extended family members also exacerbate social isolation (Myers et
al., 2009). Mothers reported an increased exposure to individuals with disabilities as a positive social effect, but this was not extended to ASD (Green, 2007).

Another significant effect of having a child with developmental disabilities is the effect on one’s marriage. Due to the caregiving responsibilities, financial burden, social isolation, and other stresses, marital issues are extremely prevalent between partners who share a child with special needs (Oprea & Stan, 2012; Hastings et al., 2005; Green, 2007; Schneider, 2017). Fathers tend to have elevated levels of stress surrounding their wives’ stress rather than associated with their child’s ASD (Baker-Ericzén et al., 2005). Hu, Han, Bai, and Gao (2019) found that in addition to strict adherence to distinct roles, “heightened demands might deplete parents’ opportunities to become highly involved in interactions with their co-parents” (p. 3994). Alternatively, other findings demonstrate marriage has the potential to be strengthened by having a child with a developmental disability (Hastings & Taunt, 2002; Myers et al., 2009). One study found that optimism and use of support increased parent relationship satisfaction (Ekas, Timmons, Pruitt, Ghilain & Alessandri, 2015).

**Existential Effects**

While not extensively researched, there is evidence that having a child or sibling with a developmental disability affects how one understands the purpose of life. Explained by Seligman and Darling (2007) as the ability of an individuals or family to “construct an explanatory meaning framework” (p. 43) for their lived experience, the existential effects of having a child or sibling with ASD rely heavily on the contextual schema of the family. Research suggests that parents of a child with ASD are likely to respond positively to survey items that are religion based or that look to God for purpose (Hastings & Taunt, 2002; Myers et al., 2009). Meaning-
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making, as both a coping mechanism and existential exercise, is a precursor for familial resilience (Myers et al., 2009; Bekhet, Johnson, & Zausziewski, 2012) and has been shown in non-disability related studies as a crucial aspect of surviving crisis (Ebersole & Flores, 1989; Cranney, 2013). Themes of hope for recovery (Oprea & Stan, 2012), being chosen as the parent for a unique child, and a positive understanding of the meaning of life were some of the most predominant existential effects expressed (Hastings & Taunt, 2002; Myers et al., 2009).

**Conclusion**

It is evident that families with individuals with developmental disabilities report positive perceptions, but this does not extend to the literature on ASD (Hastings & Taunt, 2002). While ASD researchers occasionally discuss positive perceptions, the literature specifically addressing ASD does not consistently highlight positive impacts or perceptions (Hastings et. al, 2005). It is important for individuals to understand how they are positively impacted by their family member with ASD because these attitudes are significant predictors of their quality of life. Not only is a high quality of life important for the individual, but it is also important for a family unit as the quality of life of one affects every other member (Seligman & Darling, 2007). The quality of life for parents heavily impacts the quality of life for children, especially those with ASD (Dardas & Ahmad, 2014). For this reason, it is crucial to conduct research that examines the positive impacts of children with ASD and to share these findings with other families as an encouragement and as an example of what can be cherished about their child. These findings also have implications for educators and professionals in providing related services.

**Methods**

The purpose of this qualitative study was to explore the shared experiences of immediate
family members of individuals with ASD by identifying what traits and experiences they associate with a positive outcome related to the individual with ASD.

**Design**

Through the use of a qualitative research method, a voice was given to families who are rarely asked about what positive effects their child or sibling brings to their life. Inspired in part by the emphasis on the visceral connection created by story swapping as described in Green’s 2003 study, the qualitative method was chosen to create an environment of authentic conversation to reveal in-depth understanding. By addressing the participants from the perspective of positivity, I was able to holistically address the literature gap on the positive aspects of ASD. The purpose of the study was to generate deep understanding through a posteriori variables and intimate questions. I further defined my methods to a transcendental phenomenological study to describe the realities of families through shared experience. By creating an environment for storytelling, picture showing, and bragging, the experienced positive impacts of ASD were shared honestly. In an effort to understand the experience of having a child with ASD, researchers must not look only at the negatives. One must also encourage parents and siblings by listening to the positives of their experience with ASD.

**Participants**

The target population was mothers, fathers, and siblings of individuals with ASD. This specific population enabled the research question to be answered because family members have authentic perspectives of what ASD looks like daily and therefore, provide insightful and authentic answers about the positive effects on aspects of theirs’ and their child or sibling’s life.

Participants were recruited from an email list of parents whose children are identified and
receive services for ASD in Keller Independent School District in Keller, Texas. Participants received an email from the parent-district liaison with a recruitment letter with an embedded link which led them directly to the anonymous questionnaire. There were twelve questionnaire participants, all of which reported as mothers. One participant was Black or African American, another denoted “other” as to their ethnicity, and the remaining ten were White.

The participants of the interview were far more varied. A total of twelve people participated from seven different families. A total of six mothers, three fathers, two sisters, and one brother participated in interviews. Four of the participants were Hispanic, two were Black/African American, and the remaining six were white as seen in Table 1. Ages of participants or children with ASD were not systematically collected, but were discussed during interviews. While I did not sample or control for this, three of the seven families have a child with ASD who is minimally verbal, whereas the other four have functionally verbal children. The third measure was placed during the interview, so participants remain the same for the picture presentation. Pseudonyms are used to describe families and maintain confidentiality.

**Data Collection**

The first research measure used was a researcher-created questionnaire (see Appendix A) with multiple-choice answers. I chose to design a questionnaire for descriptive purposes, rather than for generalizing. The option to write in one’s own answer was offered as one of the multiple-choice options to not limit the responses of participants who would not complete the interview. This questionnaire was used to obtain preliminary data in direct correlation to the literature review in an anonymous setting. With the question stem “Because of my child with autism…” the questions asked participants about intellectual, instrumental, emotional, interpersonal, and
Table 1

*Participant Information*

<table>
<thead>
<tr>
<th>Pseudonym</th>
<th>Gender</th>
<th>Role</th>
<th>Ethnicity</th>
<th>Child or Sibling Pseudonym</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sara</td>
<td>Female</td>
<td>Mother</td>
<td>Hispanic</td>
<td>Luis, Tomás, &amp; David</td>
</tr>
<tr>
<td>Benjamin</td>
<td>Male</td>
<td>Father</td>
<td>Hispanic</td>
<td>Luis, Tomás, &amp; David</td>
</tr>
<tr>
<td>Camila</td>
<td>Female</td>
<td>Sister</td>
<td>Hispanic</td>
<td>Luis, Tomás, &amp; David</td>
</tr>
<tr>
<td>Jessica</td>
<td>Female</td>
<td>Mother</td>
<td>White</td>
<td>Hunter</td>
</tr>
<tr>
<td>Heather</td>
<td>Female</td>
<td>Mother</td>
<td>White</td>
<td>Jason</td>
</tr>
<tr>
<td>Sophia</td>
<td>Female</td>
<td>Mother</td>
<td>Hispanic</td>
<td>DeShane</td>
</tr>
<tr>
<td>Alicia</td>
<td>Female</td>
<td>Mother</td>
<td>Black/African American</td>
<td>Leila</td>
</tr>
<tr>
<td>Darius</td>
<td>Male</td>
<td>Father</td>
<td>Black/African American</td>
<td>Leila</td>
</tr>
<tr>
<td>Nicole</td>
<td>Female</td>
<td>Mother</td>
<td>White</td>
<td>Michael</td>
</tr>
<tr>
<td>Megan</td>
<td>Female</td>
<td>Sister</td>
<td>White</td>
<td>Michael</td>
</tr>
<tr>
<td>James</td>
<td>Male</td>
<td>Brother</td>
<td>White</td>
<td>Michael</td>
</tr>
<tr>
<td>John</td>
<td>Male</td>
<td>Father</td>
<td>White</td>
<td>Noah</td>
</tr>
</tbody>
</table>

existential effects of having a child with autism. After completing the questionnaire, participants had the opportunity to follow a link to participate in an interview.

The second research method was a semi-structured interview (see Appendix B). Questions were informed by my review of the literature and personal experience working with individuals with autism and their families. Through open-ended questions directed towards participant storytelling, the participants’ responses readily revealed the complex emotions related
to ASD’s impact on their child or sibling and the impact of their child or sibling on their many facets of life. Ranging from nine minutes to an hour and fifteen minutes, the interviews became focused conversations enhanced due to common knowledge about the surrounding area and school district. Interviews were arranged via email and conducted in a setting of the participant’s choice, either in the participant’s home or a local coffeeshop. Each interview was audiotaped, transcribed, and coded by hand and through NVivo software.

The third research method was the presentation of the participants’ favorite picture of the child with ASD. Asked only of parents, this measure created a comfortable environment for the parent and invited them to share in a moment of pride. Written into the interview outline and therefore conducted during the interview, I asked “can you show me one of your favorite pictures of [child’s name]? This measure was transcribed and coded in the interviews.

Data Analysis

Questionnaire results were analyzed using Google Form charts and graphs. Percentages were calculated and write-in answers were aggregated. Questions were organized into the structure of the five different effects, intellectual, instrumental, interpersonal, emotional, and existential, as described by Seligman and Darling (2007). I deductively analyzed the themes of the most commonly answered responses for each category as well as grouped the lesser answered responses into a less prevalent themes group. Using insights from the interaction between highly recorded answers and less recorded answers, I deducted the significant attributes.

After transcribing the interviews verbatim, I open-coded the transcriptions using inductive coding techniques. I coded printed transcriptions by hand then wrote each code on a large paper (Appendix C). I then drew connections between codes and organized the codes into
themes. By surmising meaningful themes from stories, examples, and responses, I was able to draw connections between different parents and siblings to find thematic connections common throughout the interviews. Finding that the responses of the interviews fit less clearly into the categories of Seligman and Darling (2007), I created a new structure to present the results.

The transcriptions of the picture presentation or description were open-coded similarly to the interviews and themes were created from picture codes exclusively. These themes were contrasted to those from the interviews to discover if the themes were unique or corroborated the themes already presented throughout the interviews. I triangulated the findings of each set of data to corroborate and give fuller understandings and description to the themes identified.

**Results**

Participants shared their experiences, thoughts, and feelings about how having a child or sibling with ASD impacts their life and the lives of those around them for the better. Parents and siblings expressed positives that were organized into three categories: (a) identity-centered positives, (b) growth-centered positives, and (c) environment-centered positives.

**Identity-Centered Positives**

To identify what positive traits in their child or sibling with ASD family members attributed to ASD, I created questionnaire item options such as “my child with ASD cheers me up” or interview questions like “what would you miss about your child if he or she did not have ASD.” The answers revealed what parents enjoyed about their child and the traits that parents believed would either be lessened or lost without the ASD diagnosis. These identity-centered positives reflect on both who the child or sibling is, as well as how the parent or sibling perceives them. All but one participant described ASD as an integrated part of who their child or sibling is
rather than something external or as something that happened to them. Some even stated that their “child and ASD are one and the same.” The themes of enjoying humor and valuing a different perspective were identified through the triangulation of the data.

**Humor.** One of the most prevalent themes throughout every interview was the increased amount of humor added to a participant’s life due to their child or sibling with ASD. Nine of the twelve interview participants explicitly stated that their child or sibling’s humor was something that they cherished or would miss if the ASD was taken away. Questionnaire responses stating “my child with ASD is fun to be around” received six (50%) responses; three participants (25%) expressed that their child cheers them up and another two (16.7%) that their child causes unexpected pleasures in their life. One mother, Sophia, told a story of failed deceptiveness that left us both laughing aloud in a local Stabucks. She explained that her son, DeShane, after being told to resist flapping his arms on the first day of high school continued this behavior under the excuse that a bee was following him, only to smirk when confronted about it later. One mother, Jessica, described her son’s laugh as a contagious source of joy. Another participant, Nicole, raved about her son’s “dry humor. . . as the narration of [her] life.” Nicole’s two neurotypical children described similar amusement toward their brother’s humor; in the words of teenage sister, Megan, “he will just out of nowhere say something so random and it’s just so funny.” Nicole shared an image featuring her son’s personality in which herself, Megan, James, and Michael were holding hands in a line on a white sand beach. In the picture Nicole, Megan, and James were all mid-jump, while Michael stood, firmly planted on the ground, looking into the sky with a squinted face of laughter and joy. Nicole imitated what she imagined to be in Michael’s mind, “he’s just having so much fun realizing that everyone is going to jump and he’s
just gonna stay there.” Laughing at the image and shaking her head, Nicole flipped the page of the photo album and said, “and we even tried to do it several times.”

Bluntness was one of the major agents of this increased humor. All six interview participants with a functionally verbal child or sibling used the adjective or synonym to describe their child or sibling. Either through a laughable, smug comment or simply just “telling it like it is,” parents and siblings expressed that they were able to enjoy the bluntness of their child or sibling. John, a father of a nine-year-old boy with ASD, told a story of Noah’s bluntness:

One time I was doing laundry and I heard the washer slam shut and I was like “huh, okay.” I go in and before I could even ask what had happened, Noah was eating some goldfish [crackers] and abruptly yelled, “I threw the goldfish in the washing machine!” and then ran off. I thought, “okay, awesome.” He went through this big phase of throwing things in water so he’s just like that.

The descriptions of bluntness continued throughout the interviews and each was delivered with a smile on the participant’s face.

**Perspective.** Another positive effect of ASD on the child or sibling with the diagnosis was how parents and siblings perceived, valued, and were often inspired by their child or sibling’s perspective on life. Many of the participants used the phrase “unique perspective” or “looks at the world so differently” to describe their child or sibling with ASD. The codes of innocence, curiosity, and authenticity were identified.

**Innocence.** Seven of twelve interview participants used the word or described innocence as an attribute that positively altered their child or sibling’s perspective. For some, it meant being more open to others, boasting affection or interest in the people or environment around them.
Heather explained that her son with ASD was “not aware of some of the things in the world, but it’s also good.” For others, the innocence of their child or sibling protected them from the judgment of others or peer pressure to act irresponsibly. Alicia described her daughter with ASD as “a sweet girl, a loving girl, she loves to hug, she loves to play.” Alicia also described how she was able to teach life-skills to her daughter Leila, through silliness and imaginative play, despite her chronological age. Benjamin offered baby pictures on baseball cards when asked about his favorite pictures of his sons. With Bible verses where statistics would be and a picture of each son no more than a year old, he shared that he loved those because “it was still a mystery as to what future plans were for them, the innocence and purity.” Benjamin collects sports cards so the pictures of his sons on something valuable to him communicates volumes.

**Curiosity.** Described in lovingly told stories of first days of school or water table exploration, curiosity was a prevalent code, especially with fathers. Two fathers explicitly stated curiosity as one of the things they enjoyed about their child with ASD and the other alluded to it. Darius, the father of Leila, described a scene where at six months old, Leila stood in the doorway creating bubbles with her mouth. “She kept opening her mouth,” he said, “just spitting.” He explained that he has this image frozen in his mind because it was the first time he recognized that she was curiously thinking. Jessica, when asked about her favorite picture of Hunter, swiped through her phone to find a specific image. When she turned her phone around, I saw an eight-year-old Hunter standing atop a stool to reach the kitchen counter. He was draped in a large, green apron with both hands in a bowl of dough, caught in the middle of a laugh. Jessica shared this picture as her favorite because despite often playing alone, he put everything down to ask “can I wear your apron?” and join her in the kitchen.
**Authenticity.** While similar to bluntness, observed authenticity reflects the perspective of the child or sibling rather than their external comments. Comments like “he doesn’t let things cloud his judgment or worry about things that people naturally do,” and “he is very much himself all the time” communicate that participants perceive their child or sibling with ASD as generally confident and authentic.

Authenticity of spirit seen as bluntness in some individuals is understood as propensity toward extreme emotion in others. John described Noah as “giggly and goofy,” explaining that he “gets a big kick out of small things.” A similar sentiment was described by Benjamin, the father of three minimally verbal boys with ASD. He and his neurotypical daughter, Camila, shared that his sons respond to life with a joy for simple things. Sara, the mother to these three boys and Camila, stated that ASD gave her sons freedom to experience “a higher level of happiness and joy” than other boys their age. Heather, when asked about her favorite picture of her son Jason described this scene:

> When we lived in Florida, there was an abandoned train yard where the trains don’t run anymore and my husband took him there one day. Jason got to climb up on one of the train engines and he was just so excited to actually be on the train. In the picture, he’s standing on the train engine holding the cars that are right there.

She described this picture as one of pure joy because trains are his obsession and his personality shines through when he is happy.

**Growth-Centered Positives**

Parents and siblings experience growth in themselves that they also deem as positive. When asked questions like, “what are some of the positive effects your child with ASD has had
on you as an individual,” or “what do you like about having a sibling like [child’s name],” the participants reflected on their own personal growth within the context of ASD’s influence on their life. The identified themes were increased patience and changed perspective.

**Patience.** One of the most commonly reported effects of having a child with a disability with ASD, increased patience was discussed in all but three of the interviews and in ten (83 %) of the questionnaire responses as well as one write-in response. Participants described how their patience had exponentially grown because of their child or sibling with ASD. From stories about trying to travel to daily practices of waiting for their child to attend, growth in patience seemed to be important for both the quality of life of the participant and for the individual with ASD. Megan described her increased patience in the form of having to “elaborate when [she is] telling him to clean the kitchen,” showing how the increased patience of a teenage sister is different from that of a parent. Alicia also chronicled a story of patience:

For the longest time, therapists would come in and out of the house asking “what would you like us to target.” I would always say, “For her to call me mom.” It was my number one, the first thing I wanted to see. I wish that her first word had been “mom,” I tried for three years, saying “try, try mom,” but she would not say anything. So, her first word was “bubble.” That’s fine, but I didn’t give up. Like, I want mom, mom. And yet, she never said “mom.” It just kept going, she would say one or two words, but not “mom.” I came home from work one day, opened the doors. I say, “Hi Leila,” I hear “Hi Mommy.” I went “huh?” I threw everything down and turned around in disbelief. Leila laughs, “Mommeyyyyy.” I gasped. I will never forget that.

Alicia said that her daughter always does things on her own time, never when one expects it nor
when they think she is capable of it.

**Perspective.** Parents and siblings perceive the perspective of their child or sibling with ASD as distinctly different from their own and the rest of the world. John described that in trying to embrace his son’s perspective, he has found freedom to appreciate things that matter more. He said, “I think the world would be a lot better in a lot of ways if [people] saw things the way he sees things.” Having a child or sibling with ASD changes one’s perspective on the world through increased understanding, flexibility, and a unique sense of pride.

**Understanding.** The first aspect of understanding communicated was that having a child or sibling with ASD changes the way one views the world around them. One highly recorded questionnaire response was “my child with ASD makes me grateful for each day” with eight (66.7%) responses. Nicole and Megan explained that because of Michael’s quirks, they learned more about their own shortcomings and high-strung tendencies. Nine interview participants shared that they had an increased understanding and awareness of the world around them. In the questionnaire, every participant (100%) reported that because of their child with ASD, they had an increased awareness of people with disabilities. Increased knowledge about ASD was also reported by ten participants (83.3%). One questionnaire participant wrote in an answer of “I treat situations differently due to my awareness and insights of ASD.” Comments of increased empathy were common in the interviews. Darius explained that as a doctor, he had become more understanding when people canceled appointments. “I don’t know who that kid is [or] how they react in the community,” he said. Jessica shared that her son, Hunter, has taught her to be more accepting of others; her son does not judge people and she desires to resemble him in that way. James, the ten-year-old brother of Michael, said that because his brother thinks differently he
considers it “fun to see how [others] think because they always think differently.” Six (50%) questionnaire participants expressed that their other children were more aware of others’ needs and another six (50%) that their family was more aware of the importance of planning.

**Flexibility.** Increased flexibility was expressed by nine of the twelve interview participants. Described by Alicia as “in Walmart and acting a fool in front of mangoes and oranges” or by Heather as “changing expectations,” flexibility is both a physical and mental experience for families with children with ASD. Both Nicole and John used the phrase “I don’t sweat the small stuff” to describe how their perspective has changed on what is worth the energy of worry. Sara also described this phenomenon of increased flexibility, sharing that “we don’t have that much control, we just don’t; we can plan, we can prep, and it still may not work out and we have to be okay with that and not let it ruin our whole day.”

**Pride.** The questionnaire response of “my child with ASD is a source of my pride” received six participant (50%) affirmations, but illustrations of pride were scattered in many interviews and picture presentations from both parents and siblings. Two participants showed pictures that elicited a sense of pride in themselves and in their children. Sophia showed me a picture of her son in the parking lot of his high school smiling from ear to ear. He had won the student of the year award for physical education class. Sophia explained that he was always prepared, changed quickly, and did as he was told, as per his adherence to routine. She smiled at the picture saying, “he was happy because he felt like he accomplished something in a world where he always failed.” Proud of her son’s accomplishment and even happier for his pride in himself, Sophia chose this as her favorite picture. When asked about her favorite pictures of her sons, Sara brought me to one wall in her living room where school pictures were hung front and
center. She felt that it was important to make the “statement that this is a part of who we are, this is kind of a part of what makes up our family.”

Pride in how their child or sibling affected others was another aspect. “He brings so much joy to people” Jessica shared. Similarly, Darius boasted that “people gravitate toward [Leila]” accrediting it, in part, to ASD. From stories of neighborhood friends protecting DeShane from a bee with their toy baseball bats to Hunter walking across a stage to a standing, sensory-friendly crowd, clearly participants felt that ASD gave the individuals a unique social power.

Participants also demonstrated levels of pride regarding their feelings of responsibility to advocate for individuals with disabilities, whether their own or not. Camila grinned as she shared the opportunity to decorate her school locker and talk about ASD on World Autism Awareness Day. Megan shared her love for the program in her school where she would visit the special education rooms for one period to build relationships with students. Two mothers labeled themselves as “activists” and most parental interviews included at least one anecdote of having to fight for their child’s success.

**Environment-Centered Positives**

The positive impacts of having a child or sibling with ASD that were neither directed at the child nor at the participant were directed toward the environment of daily life. Questions like “what are some of the positive effects your child with ASD has had on your family” or “how is your family better because [child’s name] is in it” were asked to explore how participants viewed their child or sibling’s impact on the family. Throughout the process, other external factors unrelated to family dynamics revealed themselves. Both the effect on family and increased opportunity were identified as themes that impact the environment in which the participants live.
**Effect on family.** The family dynamic is remarkably influential on the quality of life of every member (Seligman & Darling, 2007). Across methods of data collection, family dynamics were discussed and each participant shared valuable insights related to closeness and resilience.

**Closeness.** Increased emotional closeness between family members was reported by four (33.3%) questionnaire participants. “My family is complete” elicited three (25%) responses and “my family is helped” received two (16.7%). In the interview and picture results though, nine participants expressed feelings of increased familial closeness due to their child or sibling with ASD. Sara identified her sons as the reason for their closeness, “because we literally have to rely on each other to go anywhere because they each have to have supervision.” Sophia shared that her extended family had “accommodated for him.” Because of her Latino heritage, she was surprised they accepted him so readily due to cultural expectations of machismo. Married participants shared that having a child with ASD strengthened their marriage. For example, Heather said that they had “to draw closer together because there’s been several times where there’s just people who don’t understand.” Some participants were closer because of the need to communicate and rely on each other to survive. Epitomizing this familial closeness, Darius’ favorite image was about his daughter needing him. He described the context of traffic and being late to pick Leila up from daycare, “she stood right there at the door, the glass door, and she was just looking, they were going to turn off the light and she was just looking to see if I’m coming to pick her up.” When she saw him, she threw up her arms, ran, and jumped into his arms. Similarly, Darius’ wife, Alicia, also showed a picture representing the closeness between Leila and her father. She chronicled the story of Leila’s first Halloween. Adorned in a princess gown and tiara, she held her father’s pinkie who “dressed as a doctor that day.” Leila was “looking up
at Daddy, that was so incredible,” Alicia shared.

**Resilience.** The family’s ability to adapt and thrive in atypical situations is described as resilience. This code was expressed in the questionnaire though eleven (91.7%) responses of “my family is more understanding of unique situations,” and was discussed in interviews and picture presentations primarily in descriptions of the small successes that families with children with ASD experience that other families do not. Nicole explained:

I love all my kids, they’re different, the standard parent thing we all love our kids differently but we love them the same, you know. But Megan doing good on a test and Michael doing good on a test, her making a friend and him making a friend are completely different. I’m more invested and prouder of him in ways that other parents just never get the opportunity to be proud in those ways. And the things he overcomes, as a parent, I can’t imagine not getting those little victories. I wouldn’t know I wasn’t totally fulfilled, raising all these typical kids, but it’s a lot more than just overwhelming. There’s so many different emotions and experiences and challenges and growth opportunities that come to you when you have a kid on the spectrum and I wish it was looked at more as an opportunity or a challenge.

A similar sentiment was described by John, Sara, Darius, and Alicia; the little victories “are worth the fight.”

**Increased opportunity.** The codes of career opportunity and opportunity to make meaning were identified by participants as part of their purpose in having a child with ASD.

**Career.** One questionnaire participant (9.1%) cited an improved work life as a positive aspect of having a child with ASD, whereas four interview participants indicated that they felt
having a child with ASD was advantageous to their career. As a pharmacist, Alicia stated that her daughter’s experience prompted her to taste every medication she distributes in an effort to properly mix flavoring. Sophia, a diagnostican, and Heather, a special educator, both credited their child with ASD with the advancement of their careers. They learned more about the field and could better relate to other parents. Sara also uses skills from her social work career to advocate for her sons.

**Meaning-making.** Three participants described their experience of meaning-making. Sophia described a period of guilt in which she blamed herself for her son’s diagnosis, but eventually decided that “[she] got a blessing, God chose [her].” Jessica explained that she believes Hunter has a unique relationship with God and said, “I have this angel that the Lord trusted me enough to take care of.” Faith in God was confirmed for five (41.7%) questionnaire participants and frequent attendance of religious services was reported by one (8.3%). In a scenario of talking to another family with a child with ASD, Nicole asserted, “God has presented you with this unique challenge for your family like how special are you guys!” The questionnaire response of “I know there is purpose in life” received seven (58.3%) participant responses.

**Discussion**

Using multiple methods for data collection allowed for a deeper understanding of the positive aspects of life with an individual with ASD. The use of a closed response questionnaire, open-ended individual interview, and a stimulus aided prompt (i.e., a photograph) demonstrated that the latter two yield more diverse answers than the first. This finding demonstrates that when given an open-ended avenue for families to speak about their experiences, the result and therefore meaning is personally contextualized. The triangulation of the three forms of data
collected revealed both commonalities and differences. For example, the questionnaire results showed limited response to increases in interpersonal benefits, whereas the interview results showed that participants were encouraged by the influence of their child on their social life, particularly in reference to advocacy. Commonalities between the interviews and picture presentation were frequent and led to the majority of the codes and subsequent themes. Throughout all methods though, participants identified and communicated that ASD had not ruined their life, only changed it. While no researchers assert that children with ASD ruin lives, this conclusion can be assumed when data shows increased stress across all domains of life (Simson, 2013). All participants shared at least one specific way that their child or sibling with ASD had positively influenced them, their environment, or the individual.

Identity-centered positives were some of the clearest positive aspects of life identified by parents and siblings throughout all methods. Contrary to the research by Hines et al. (2011), all but one participant described their child’s identity as integrated with their ASD. Interestingly, the participant who identified their child as separated from ASD later listed her daughter’s diagnosed speech delay as part of her identity. This finding seems to indicate that identity and language are more closely related than identity and behavior. This conclusion is supported by the finding that most of the positive effects identified by families were significantly impacted by the child’s verbal ability. Codes like bluntness were exclusive to families with functionally verbal children, but the themes of humor and perspective were universal. The emotional process of understanding one’s child or sibling’s identity was expressed by many participants as a generally positive experience, at least in the present. While I asked families about their diagnosis story, I did not specifically ask about the emotional state surrounding the diagnosis and cannot therefore
contribute to Oprea and Stan’s (2012) conclusions about the intellectual trauma of diagnosis. The aftermath of the diagnosis though, as Green (2007) stated and my data corroborates, results in families’ adjustment and acceptance. This acceptance of the individual with ASD can become valued, as shown through the emphasis on the qualities of humor and perspective in family members with ASD. The fact that family members would share that ASD is crucial to positive aspects of the identity of their child or sibling is significant because it shows that family members surpass the original trauma, even acceptance, and can express a level of desirability.

Seligman and Darling (2007) stated “what affects one [family] member affects all members” (p.17). They explain that in a sense, when one family member is Deaf, all members are Deaf. This concept can be extended to ASD in that, when one family member has ASD, the entire family acts out of awareness and consideration of ASD (Seligman & Darling, 2007). Families in past literature seem to jump at the opportunity to share their care-giving burdens (Estes et al., 2009; Vasilopoulou & Nisbet, 2016; Wayment & Brookshire, 2017; Myers et al., 2009; Dardas & Ahmad, 2014; Green, 2007). Families in the current study though, while asked about the positives, were given an open-ended response and could have shared the burdens, but rarely did. Participants expressed personal growth through increased patience and a new perspective on life. These same traits were identified by parents as the ways their neurotypical children had been affected. Increased patience is one of the positives found by Myers et al. (2009), but is expanded upon in my findings. Pride in one’s child or sibling with ASD appears to be a new theme in the research of ASD, though it has been discussed in relation to disability as a whole (Green, 2007). Through Seligman and Darling’s (2007) systems approach to childhood disability, when parents and siblings treasure the growth of their family member with ASD, the
value extends to self-growth. That is, when the entire family has ASD, any amount of growth or any “little victory,” as Nicole coined, is celebrated.

The environment-centered positives found in this study are consistent with the concept that families are complex and interdependent systems (Seligman & Darling, 2007). Increased family closeness, even in families with separated parents, was a common response. Similar to past research, a child or sibling with ASD has the potential to be beneficial for a family (Hastings & Taunt, 2002; Myers et al., 2009), or potential to be detrimental (Schneider, 2017). My finding that some individuals express increased pleasure in their career is reflective of Hastings and Taunt’s (2002) research.

**Limitations and Recommendations for Future Research**

While in-depth understanding of the experiences of parents and siblings of children with ASD was gained, transferability of findings to others is limited due to participants originating from one school district in North Texas. Despite its narrow scope, this research prompts the conversation for further investigation into the positive aspects of ASD on children and their families. Aligned with the neurodiversity movement that bolsters the thought that individuals with ASD have unique qualities that are an asset to them and their environment, positive aspects of ASD should continue to be researched. It is also worth noting that further research into the discrepancy between the Hines et al. (2011) research and my findings on parental differentiation between their child’s identity and their child’s ASD diagnosis, especially within the context of comorbid language delay, would be advantageous to the field. My findings alluded to the concept that parents of a child with ASD and a diagnosed speech delay may be more likely to separate their child from ASD and integrate the speech delay into their child’s perceived identity,
as opposed to parents of children without comorbidities identifying ASD as part of who their child is. My study can encourage future research, but also encouraged the participants, which could be argued is the most important result of the study. Every parent thanked me for letting them brag about their child, for helping to open other’s eyes to the fact that ASD “is not a death sentence,” and for beginning the conversation about the strengths of their children. By asking alone, participants were reassured and inspired to see the positive aspects of ASD, creating a positive environment. While it cannot be quantified through this study, research has shown that positive parental perception leads to better outcomes (Dardas & Ahmad, 2014). If asking such questions is a catalyst to increased familial satisfaction, then that’s a valuable finding.

Conclusion

Parents and siblings of individuals with ASD provided in-depth emotional analysis and anecdotes regarding their child or sibling with ASD. I identified that parents and siblings of individuals with ASD attribute positive traits in their child or sibling’s identity, their own personal growth, and positive environmental changes to having a family member with ASD. From the thematic analysis of all measures, it can be stated that for these seven families, ASD has positive effects that parents and siblings are willing and excited to share.

For professionals, these results are important for interventions and the initial diagnostic process. If professionals are aware of the positives associated with having a child or sibling with ASD, they can share that information with families. Families can also be encouraged by these findings as they search for their own stories in the anecdotes and quotes expressed by the participants. As the pursuit of optimism is depicted, the continuation of this pursuit in other families can be fostered. Arguably most importantly though, this research has implications for
individuals with ASD. Research that seeks to emphasize the qualities that individuals with ASD boast can encourage neurodiverse populations to confidently share their talents with the world. Affirming that ASD is a uniquely challenging and rewarding circumstance, these results can empower the ASD community towards self-advocacy.
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ASD and Positive Familial Effects

*Behavioral Sciences, 46*, 4191-4194. doi:https://doi.org/10.1016/j.sbspro.2012.06.224


Appendix A

Questionnaire

CONSENT FORM
Autism Spectrum Disorders and Positive Familial Effects
Genevieve Weaver
Liberty University
School of Education

You are invited to be in a research study regarding the daily lives of families with individuals with autism spectrum disorders, specifically, looking at the positive impacts that immediate family members gain from their child or sibling with autism. You were selected as a possible participant because of your immediate familial connection (mother, father, sibling) of an individual/individual's identified or diagnosed with ASD. Please read this form and ask any questions you may have before agreeing to be in the study.

Genevieve Weaver, a student in the School of Education at Liberty University, is conducting this study.

Background Information: The purpose of this study is to better understand the daily lives of families with individuals with autism spectrum disorders, specifically looking at the positive impacts that immediate family members gain from their child or sibling with autism.

Procedures: If you agree to be in this study, I would ask you to do the following things:
1. Complete a questionnaire regarding the positive impacts of your child with ASD on varying aspects of your life. The questionnaire should take about 20 minutes to complete.

Risks: The risks involved in this study are minimal, which means they are equal to the risks you would encounter in everyday life.

Benefits: Participants should not expect to receive a direct benefit from taking part in this study. Benefits to society include giving the world examples of families who have found joy in their situation. By sharing what, arguably the most affected group of people, have gained from having an immediate family member with ASD, society will have greater access to information regarding what individuals with ASD bring to society. With a shift of perspective towards the positive impacts of ASD, hopefully, more people, especially other family members, will begin to see the unique and important role individuals with ASD play in our world.

Compensation: Participants will not be compensated for participating in this study.

Confidentiality: The records of this study will be kept private. Research records will be stored securely, and only the researchers will have access to the records.
- Participant responses will be anonymous.
- Data will be stored on a password locked computer and may be used in future presentations. After three years, all electronic records will be deleted.

Voluntary Nature of the Study: Participation in this study is voluntary. Your decision whether or not to participate will not affect your current or future relations with Liberty University. If you...
decide to participate, you are free to not answer any question or withdraw at any time without affecting those relationships.

**How to Withdraw from the Study:** If you choose to withdraw from the study, please exit the survey and close your internet browser. Your responses will not be recorded or included in the study.

**Contacts and Questions:** The researcher conducting this study is Genevieve Weaver. You may ask any questions you have now. If you have questions later, **you are encouraged** to contact her at 817-675-3668 or gkweaver@liberty.edu. You may also contact the researcher’s faculty advisor, Dr. Lucinda Spaulding, at lspaulding@liberty.edu.

If you have any questions or concerns regarding this study and would like to talk to someone other than the researcher, **you are encouraged** to contact the Institutional Review Board, 1971 University Blvd., Green Hall Ste. 2845, Lynchburg, VA 24515 or email at irb@liberty.edu

**Please notify the researcher if you would like a copy of this information for your records.**

**Statement of Consent:** I have read and understood the above information. I have asked questions and have received answers. I consent to participate in the study.

1. **I have read the attached consent form.** *
   
   *Mark only one oval.

   - [ ] Yes
   - [ ] No **Stop filling out this form.**

**Demographic Information**
2. Please specify your ethnicity.
   Check all that apply.
   - American Indian or Alaskan Native
   - Asian
   - Black or African American
   - Native Hawaiian or Other Pacific Islander
   - White
   - Unknown
   - Other

3. I am the _______ to a child with autism spectrum disorder.
   Mark only one oval.
   - Mother
   - Father
   - Parental Guardian

Positive Impacts of ASD
Within the following categories, please check all options that you feel best describe your perspective of the positive impacts of ASD.

4. In what ways does your child with ASD affect your immediate family?
   Because of my child with ASD...
   Check all that apply.
   - my family is emotionally closer.
   - my family is more understanding of unique situations.
   - my other children are more aware of others' needs.
   - my family is aware of the importance of planning.
   - my family is complete.
   - my family is helped.
   - Other: ____________________________
5. **In what ways does your child with ASD affect your social life?**
   Because of my child with ASD...
   *Check all that apply.*
   - [ ] I have closer friends.
   - [ ] I have a larger group of friends.
   - [ ] I have a newfound interest in social activities.
   - [ ] I feel more connected to the world.
   - [ ] I have common ground with other parents.
   - [ ] Other: ____________________________

6. **In what ways does your child with ASD affect your perspective on life?**
   Because of my child with ASD...
   *Check all that apply.*
   - [ ] I know that there is purpose in life.
   - [ ] I am confirmed in my faith in God.
   - [ ] I more frequently attend religious services.
   - [ ] I am more aware of the future of humanity.
   - [ ] Other: ____________________________

7. **In what ways does your child with ASD affect your daily practicality?**
   Because of my child with ASD...
   *Check all that apply.*
   - [ ] I have better structure in my life.
   - [ ] I am more responsible with money.
   - [ ] I am more responsible with time.
   - [ ] I am more productive.
   - [ ] my work life/career is improved.
   - [ ] my home is cleaner or more organized.
   - [ ] Other: ____________________________
8. In what ways does your child with ASD affect your learning?
Because of my child with ASD...
Check all that apply.

- [ ] I have learned about ASD.
- [ ] I have learned about my own biomedical or sensory needs.
- [ ] I have learned how to be a better parent.
- [ ] I have an increased awareness of people with disabilities.
- [ ] I can handle intellectual challenges better.
- [ ] Other: ____________________________

9. In what ways does your child with ASD affect your emotional wellbeing?
My child with ASD...
Check all that apply.

- [ ] causes many unexpected pleasures in my life.
- [ ] makes me grateful for each day.
- [ ] is a source of my pride.
- [ ] cheers me up.
- [ ] is fun to be around.
- [ ] Other: ____________________________

Please consider participating in an interview.
The interview extension of this questionnaire allows the researcher to see a fuller picture of the nature of the positive impacts of ASD on a family. The interview process would consist of questions for both parents and siblings, if applicable, and would take place at a location of your choice. The interview would take about 30 minutes per parent and 15 minutes per sibling.

To maintain the anonymity of your questionnaire responses, your contact information will be separated from your questionnaire responses through the use of an additional form. The data will be provided to the researcher in separate forms.
10. **If you are interested, please follow the link to set up an interview**
(https://forms.gle/UQorSGrpsPzyQnzU7)

*Mark only one oval.*

- [ ] I will follow the link
- [ ] No thanks
# Appendix B

## Interview Outline

**Interview Outline**

Note: Researcher will replace blanks in the question with the name of the individual’s child with ASD.

### Parent Interview:

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What general positive impacts do parents of individuals with ASD identify with their affected child?</td>
<td>Can you show me one of your favorite pictures of _____? Why is this a favorite picture?</td>
</tr>
<tr>
<td></td>
<td>Can you tell me one of your favorite stories regarding your child with ASD? Why is it a favorite?</td>
</tr>
<tr>
<td>What positive impacts on personal life do parents identify with having a child with ASD?</td>
<td>What are some of the positive effects your child with ASD has had on you as an individual?</td>
</tr>
<tr>
<td></td>
<td>How would you describe your relationship with ASD?</td>
</tr>
<tr>
<td>What positive impacts on family life do parents identify with having a child with ASD?</td>
<td>What are some of the positive effects your child with ASD has had on your family?</td>
</tr>
<tr>
<td></td>
<td>How has _____ positively affected each family member?</td>
</tr>
<tr>
<td>What positive impacts on their child’s life do parents attribute to ASD?</td>
<td>What are some of the positive effects ASD has had on your child?</td>
</tr>
<tr>
<td></td>
<td>What traits would you miss about _____ if he/she didn’t have autism?</td>
</tr>
</tbody>
</table>

### Sibling Interview:

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>What general positive impacts do siblings of individuals with ASD identify with their affected sibling?</td>
<td>Can you tell me one of your favorite stories about _____? Why is it a favorite?</td>
</tr>
<tr>
<td></td>
<td>- If child struggles to self-generate a story, the researcher will give the prompt of “Can you tell me a story about a time ____ helped you?”</td>
</tr>
<tr>
<td>What positive impacts on personal life do siblings identify with having a sibling with ASD?</td>
<td>What are some things that you like doing with _____?</td>
</tr>
<tr>
<td></td>
<td>What do you like about having a sibling like _____?</td>
</tr>
<tr>
<td>What positive impacts on family life do siblings identify with having a sibling with ASD?</td>
<td>How is your family better because ____ is in it?</td>
</tr>
<tr>
<td>What positive impacts on their sibling with ASD do siblings attribute to ASD?</td>
<td>What would you miss about _____ if he/she didn’t have autism?</td>
</tr>
</tbody>
</table>
Appendix C

Open-Coding