



**Eximia Journal**  
**(ISSN 2784-0735)**

**Vol. 9**  

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**2023**

## **Transformed by Parenting Experience: Perspectives, Challenges, and Optimism of Parents of Children with Autism Spectrum Disorder in Their Adulthood**

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**Abstract.** Background. Parenting a child with autism spectrum disorder comes with many insights, challenges, and seeing the silver lining from experience. Parents with children under the spectrum are exposed to much exhaustion. As unique as the characteristic of the child's disability, they all have different types of struggles. The researcher is a special needs teacher who has handled children with different types of disabilities and bonded with their parents over the years. Although their experiences have similar patterns, they have unique insights that many fail to see. Furthermore, the researcher, who has a great interest in the parents' varying visions in life, conducted a study to dig deeper into their experiences, troubles, and how their life encounters are extraordinarily exceptional compared to regular parents. The paper explores their life dynamics, mindset, skills, and realizations through qualitative phenomenological lenses. Methods. The qualitative research approach and phenomenology were utilized to explore and understand the unique experiences of parents raising their children with autism in adulthood. The process of the study involved emerging questions and procedures, data typically collected in the participant's setting, data analysis inductively building from particulars to general themes, and the researcher making interpretations of the meaning of the data. Results. The qualitative data analysis revealed that parents with children with autism in their adolescence follow similar, although not all, experiences from the moment they discover the diagnosis until learning to accept their reality and raising their children. They have similar types of challenges and realizations while raising these children. Unlike some people, when faced with very tough trials in life, they do not have the option to quit their role nor have the liberty to change their situation and steer their path in life in a different direction. Giving up is not in their books, and they continue life as parents and face their challenges head-on. Furthermore, the qualitative data generated three major themes, namely (1) Insights on Parenting of Children with Autism in their Adolescence with five subthemes, (2) Difficulties and Struggles in Parenting a Child with Autism with seven sub-themes, and (3) Seeing the Silver Lining in Being Parents to a Child with ASD with five sub-themes. Conclusion. The journey of parents in raising children with autism comes with varying challenges that are different from the regular parents with typically developing children experience. Generally, parents of children with ASD would start by sharing many endless struggles. Although they will always have similar struggles, each parent has a unique experience with their child's disability. Their experience is their best teacher in knowing how to cope with their unique struggles, which come in different levels of severity; hence they become braver in facing difficult situations which have to be dealt with no matter what. Parents who have spent more years in their experience in raising a child with ASD, such as in their adolescent years, already have more insights and usually see the silver linings in raising them compared to parents who just started this similar journey. These parents garnered many realizations about themselves and their purpose and became transformed in their lives. Practical

Value of the Paper. The study will benefit parents with children with autism or any form of disability who feel uncertain about their journey of raising a child with autism and wonder what the best thing to do for their child is. When they encounter studies like this, they will learn the common patterns of experienced ASD parents, navigate clearer on what to expect, gain useful insights, and have emotional support. They will realize they are not alone and that many other parents are going through the same thing. This is also beneficial for special needs teachers who have first-hand experience with these parents and will have a broader understanding of what they are going through. Understanding what they are going through will help them build a good rapport and make academic planning for their child easier. Directions for Future Research. This study will serve as a baseline for future research on lived experiences of mothers of children with autism. The patterns and other findings about their experiences can be used to enhance further research about family experiences for those who have members with disabilities. They can go beyond the scope of this study and tap into other concerns related to the results. Possible changes or progress could be related to the study, and future researchers can continue the topic with different or better findings. They can recognize the limitations of the current studies on this topic and may add significant revisions for better public involvement.

**Keywords.** Social sciences, parenting experience, autism, qualitative, descriptive, Philippines

## INTRODUCTION

### Background of the Study

Parenting is said to be much easier if children come with an instructional book. Parenting entails responsibilities and challenges. Moreover, the responsibilities and challenges of parenting children with special needs are compounded. Parents of children with special needs suffer more than regular parents, and they, too, just like their unique children, sometimes seek professional support (Wolfe, 2020). Raising a child with special needs poses a lot of trials and unique parenting-related kind of burdens. Many studies have explained how these parents cannot avoid it and are often subjected to various kinds of stress daily. They know there is no other way to deal with it but face it and be the best parents to their child even though the road ahead for their child may be unclear. Every now and then, people may raise eyebrows about their family life, but they know they must live a life of their kind of normal. The increase of special needs children gives more challenges to more families, yet parents learn to manage their child's diagnosis (Downey, 2016).

Moreover, families who have children with autism experience more stress than other families with a member diagnosed with a disability. Raising these kids with autism is far more taxing and beyond stressful because of the nature of the disability that needs to be addressed by the caregivers (Saris, 2019). There are a lot of difficult behaviors, and they differ among individuals, such as picky eaters, uncontrollable meltdowns, and hyper or hyposensitivity with their senses, to name a few. To manage these behaviors, they prevent them from running away, calm them down and prompt them visually or auditory to suggest appropriate behaviors and responses to others (Lopez & Wiskow, 2020). Simply put, these parents of children under this spectrum are inevitably exposed to immeasurable exhaustion and stress, yet they are so focused on their child's needs that they do not see their health problems.

In the Philippines, parents of children with autism have varying perceptions and approaches to autism and how to deal with it. Generally, they have an unresolved idea of the impairment's etiology, yet they have similar takes on the psychosocial factors that come with it as a parent (Quilendrin et al., 2015). During the pandemic, the parents of these children also

had to face some similar struggles, such as being the parent and the teacher at the same time, devising ways for the child to understand the sudden transition from face-to-face to online schooling, applying the behavior management strategies at home without the paraprofessionals and making them understand the social reality hence preparing them for what may be after the global emergency (Cahapay, 2020).

Here in the Philippines, there is a surge of cases of ASD, from 500,000 in 2008 to roughly 1 million by 2018 (Lambatin, 2018), while some are undiagnosed. Parents in the Negros province experience similar struggles to other parents in raising their children with autism. They go through different therapies, collaborate with professionals, become advocates of autism, and support groups that promote autism awareness. Still, in the same province, fathers of children with autism encountered many challenges raising them during the pandemic due to the sudden changes in their routines. At the same time, they also found fulfillment in their role as a parent to their unique child (Jardenil & Madrigal, 2022). However, there is still a dearth of studies about the experiences of parents of children with autism in Negros.

The researcher is a general education teacher, a special education teacher, and a SPED Program Coordinator, and over the years, she found her purpose in her profession. She has met transformational parents who have inspired and motivated her to see the good in a difficult situation and have taught her to treat everyone equally despite diversity. Her experiences made her more aware that there are a lot of self-sacrificing parents of children with special needs, and they have taught her so much about the value of giving and gratefulness. How do they boost themselves and stay positive while realizing their role fulfilled in parenting this child? How do these parents keep going and fighting and juggling other responsibilities at home, at work, and in the community while bringing up this child? This is something worth discussing and studying in this world full of diversity.

Much research has been done on the coping mechanism of special needs parents, the burnout level of parents, the stress levels of these parents in dealing with their children, and many more negative attributes attached to being parents of special needs children. There is a dearth of studies on their positivity than the opposing side. More support and services from society should be offered to these parents to lessen their burden in raising their children. It is something that the researcher strongly finds more important to focus on rather than identify the disadvantages of this situation. With the scarcity of literature on the positivity of parenting children with autism, the need to conduct the present study has been established.

### **Purpose Statement**

This phenomenological inquiry intends to explore and uncover the "essences" of meaning in lived experiences of parents of children with autism on Negros Island. The constructivist perspective will assist in articulating the parents' experiences.

Moreover, this research seeks to uncover the essence of the parents' answers to the question: What are the lived experiences of parents of children with autism?

### **Review of Related Literature**

The researcher has related and anchored this paper to other studies and articles about parents who have children with special needs, especially the ones with autism. Generally, they have received a lot of social stigmas, insurmountable stress, situations to problem solve, shed tears, felt guilt, happiness, overwhelming love, humiliation, self-fulfillment, self-doubt, and varying unique experiences other regular parents would never have to go through. The list goes on how they deal with life's trials. Many people may never come close to understanding or even

knowing, yet it is something that society should not shrug off nor turn away from. The researcher has met many of them in her teaching profession, and not one has ever had such an easy life raising their child.

**Insights on parenting a child with autism.** Without a doubt, having a child with autism or any disabilities will cause a higher level of stress to parents and the entire family because of the excessive caregiving demands and unusual behavior patterns the nature of disability comes with (Downey, 2016). Parenting a child with special needs commonly follows a similar pattern among parents. They start with the grief of knowing the diagnosis, processing their feelings upon acceptance, facing the problem by making plans and goals for the child, having different sorts of concerns constantly daily, experiencing problems, and finding meaning in their experience (Kocabıyık & Fazlıoğlu, 2018).

Challenges of raising a child with autism may vary in type, but they are usually experienced constantly or daily. Life, experiences, and constant concerns are often undervalued and underrated by society. What they have to say or share remains within the corners of their zone and only among people or professionals they team up with. Many of them claim they receive unhelpful support experiences and must compensate for the lack of knowledge about autism from society (LaRoche & des Rivieres-Pigeon, 2022). Couples often fight over many things on child-rearing-related issues, causing a rift between spouses. Simply being parents to a child with autism attaches other sorts of marital problems, and in addition to their challenges as a couple, they are confronted with different parenting demands.

The study by Downes and Cappe (2021) investigated different factors associated with co-parenting styles and the life of parents. The evidence suggested that even the severity and type of autism of the child also affected the couple's way of life and their relationship. Another problem noted is the unavoidable skyrocketing stress level parents always face. A study of 176 couples recorded a high level of stress for both parents and even positive interactions gave mothers more stressful parenting days (Hartley et al., 2018). Similarly speaking, to date, numerous studies have revealed that parents of children with ASD experience a much higher stress level compared to parents of other developmental disabilities (Sinha et al., 2016).

**Difficulties in raising a child with autism.** Moreover, the stress of dealing with their child's unusual, difficult behavior patterns, they also experience different kinds of social stigmas continuously from strangers and people close to them. There has not been a parent of a child with autism who never experienced any sort of discrimination or autism stigmas. When the child displays aggressive or inappropriate behaviors, most mothers claim they experience avoidance, hostile staring, and rude comments from people around (Gray, 2002). This makes them feel ashamed, inferior, and excluded, which may later make them prefer to isolate themselves in social situations.

This is what some researchers have pointed out, and in one study, more than 65% of these children and their families were often avoided by people and left out of activities, and some 13% were physically bullied at some point (Saris, 2019). In addition to bullying, the study, which interviewed roughly 500 parents of children with autism, reported several serious problems that occurred either sometimes or often, and of them is more than a third of the children were teased and insulted, and 22% were called hurtful names (Fischbach, 2015). Parents have a hard time letting their children fit in socially, affecting their child's social life and theirs.

Another noted point was that parents think many people have already harbored autism stereotypes. In the same study, parents claim that raising a child with autism is hard. About 18 percent said it was extremely difficult, 32 percent said it was very difficult, and 40 percent said it was somewhat difficult (Fischbach, 2015). The social stigmas often stem from the bad

behavior of the child with autism, which people witness and get all sorts of criticisms and unsolicited advice, making them feel like they are bad parents. There is still an enormous amount of ignorance among the general population regarding understanding the autism spectrum, which worsens things for parents raising these children. There are so many things they wish people would know.

As a special needs teacher, the researcher knows there is a consistent rift in communication between teachers and parents, and often it is caused by the parents' inability to express and verbalize the issues they want to say. Parents are most often not mental-health experts, but they are experts in knowing their children. However, they are also not experts on having plan b when they are declined by society. There are advocacy groups they can turn to, and they also need to know that there is external help they can seek, yet many of them do not know the obligation of society to them (Eicher, 2018).

Furthermore, raising a child with autism can be costly too, and the impact of raising them can put serious financial constraints on the family's income in several ways. Adjusting to the child's condition and needs affects the family's housing and finances, contributing to parental stress (Begum & Mamin, 2019). They are not only limited to the intervention fees but also to medications, access to materials they need for school or to address their other needs, food preference, special clothing, doctor's fees, and so on. It is said their cost is 18% higher than what one can spend on regular kids (Befkadu & Adamek, 2022).

On the other hand, parents do not allow themselves to wallow for a long time, and they do discover ways to cope in such situations. Coping is any conscious and unconscious way of adjusting that may decrease tension and anxiety in a stressful situation. Parents in this study had their ways of accepting the situation finally so they could move on and realistically plan for their child. There may be different techniques for coping mechanisms between mothers and fathers of children with ASD (Haytham et al., 2022), but whatever it is, they use it to come to terms with their situation. Attunement to their child's reality may seem hard at first, and they go through a series of grief. However, later, accepting makes things easier to deal with. Studies show they go through stages of grief like denial, anger, and bargaining eventually leads to accepting their child and their situation. It teaches them to control their situation and better handle their struggles (Mansur et al., 2022).

According to Kubler Ross, people usually pass through a sequence of grieving which is a tool for us to frame and identify our feelings. Some may not complete the five stages, such as denial, anger, bargaining, depression, and acceptance, while others do and may have more steps, but it equips us to cope with life's challenges and losses (Ross, 2022). Likewise, they know their child needs them, and being the sole caregiver, they all have to sacrifice something themselves, such as self-goals and career advancements, for the proper development of the child. They rest in the idea that their child will get better the more time they spend with them in their growing years, being as available as possible during important milestones. They do this to balance their family life, maintain a career and raise a child with special needs (Bainbridge & Brody, 2017).

**The positive side of raising a child with autism.** Through it all, the parents find the silver lining in their situation of having a child with ASD. Most studies explore and reveal other experiences, most especially the struggles of these parents, but a few only talks about the silver lining. There is a dominance of research focusing on the negative aspects and consequences of having a child with autism. However, there is little study on the positive aspects of the caregiving experience (Meleady et al., 2020). The silver lining refers to the positive side despite the adversities of raising a child with autism.

Seeing milestones unfold before them is everything, but it may seem nothing out of the ordinary to others. They do not give up on the power of interventions, and the positive results impact the parents' self-efficacy and how competent they are as parents (Estes et al., 2021). This indicates that their efforts are paying off and their child is finally getting better, and each sign of improvement is special for parents. All participants in this study take pride in sharing their child's genuine and no-filter personality, which they feel sets them apart from other regular children because they might not show their love as authentic as their children do. Some claim they have been lucky in some aspects of their lives since they had their child despite the difficulties.

Parents claim that the experience of raising a child with autism has pushed them beyond their threshold for everything. Because of this, it has taught them valuable life lessons and resilience to challenges in life. Silver linings can differ among parents since their experiences with the same parents are unique. Seeing the positive side takes a while to be discovered because parents need a lot of experience to get to that level. Parents of ASD children with more positive contributions and higher psychological well-being and relationship satisfaction are those whose kids belong in the older age bracket. Hence it coincides with this study (Meleady et al., 2020).

Over the years of ups and downs, failures and triumphs, parents become more aware and experienced and gained many effective strategies to handle difficult situations and cope with their problems. As they say, experience is the hardest teacher. It gives you the test first and the lesson afterward. Since parents of children with ASD usually do not give up and just keep moving forward with their child, they eventually find more ways to deal with it more effectively, thus increasing their ways to have social support and develop post-crisis growth (Alon, 2019).

In vast studies on parental experiences, one can find a dominance of negative experiences of families coupled with tragedy model interpretations. Generally, mothers are more hands-on with their children. However, even when fathers with lesser participation in the child's activities and therapies are interviewed further, they also see the silver lining in parenting a child under the spectrum. In a study where 198 fathers to children with autism were interviewed, they shared the good side of having a child with autism, appreciated their children's unique qualities, valued their strong emotional bond with them, and admitted to their personal development from their experience (Potter, 2016).

## **Methodology**

**Research design.** This research study utilized a Descriptive Phenomenology research approach and Qualitative as the research design. Qualitative research is an approach to exploring and understanding the meaning individuals or groups ascribe to a social or human problem. The research process involves emerging questions and procedures, data typically collected in the participant's setting, data analysis inductively building from particulars to general themes, and the researcher interpreting the meaning of the data (Creswell & Poth, 2016).

A phenomenological study describes the common meaning for several individuals of their lived experiences of a concept or a phenomenon. Phenomenologists focus on describing what all participants have in common as they experience a phenomenon. The basic purpose of phenomenology is to reduce individual experiences with a phenomenon to a description of the universal essence (a grasp of the very nature of the thing) (Van Manen, 2016).

The researcher explored the lived – experiences of the parents of children with autism. The researcher's exploration procedure is well-fitted for a qualitative approach. The

phenomenological research design is well-suited to uncovering the universal "essence of the meaning of the lived experiences of parents of children with autism.

**Philosophical assumptions.** The philosophical assumptions are embedded within interpretive frameworks that qualitative researchers use when they conduct a study. Thus, Denzin and Lincoln (2011) consider the philosophical assumptions (ontology, epistemology, axiology, and methodology) as key premises that are folded into interpretive frameworks used in qualitative research.

In this qualitative research, the worldview or interpretive framework the researcher will use is constructivism or social constructivism (often described as interpretivism) (Denzin & Lincoln, 2011; Mertens, 2010 cited in Creswell & Creswell, 2017).

Social constructivism explains that individuals seek an understanding of the world in which they live and work. Subjective meanings of their experiences are developed. These meanings are varied and multiple, leading the researcher to look for the complexity of views rather than narrow the meanings into a few categories or ideas. The goal of the research, then, is to rely as much as possible on the participants' views of the situation. The researchers generate or inductively develop a theory or pattern of meaning (Creswell & Creswell, 2017).

The following are the philosophical assumptions made in the undertaking of this study.

**Ontological assumption.** The ontological issue relates to nature or reality and its characteristics. In the conduct of qualitative research, the researcher embraces the idea of multiple realities. Evidence of multiple realities includes using multiple forms of evidence in themes using the actual words of different individuals and presenting different perspectives (Moustakas, 1994 cited in Creswell & Creswell, 2017). Parents of children with special needs experience joy and sadness and, without a doubt more exhausted than parents of typically developing children. Being a parent to a child with special needs comes with many challenges and problem-solving skills compared to parents with typically developing children, yet they also experience more self-fulfillment. There is a mix of the onslaught of stress daily, unanswered questions, doubts about self, and social problems; hence they are also learning a lot. This assumption guides the researcher to embrace the idea of multiple realities experienced by the parents.

**Epistemological assumption.** With the epistemological assumption, conducting a qualitative study means that researchers try to get as close as possible to the participants being studied. Subjective evidence is assembled based on individual views. Through the subjective experiences of people, knowledge is known. The researcher tries to minimize the "distance" or "objective separateness" between herself and those being researched (Guba & Lincoln, 1988 cited in Creswell & Creswell, 2017). The researcher will spend time with the participants, initially establishing rapport, as intended before, during, and after the interviews. Further, the researcher will rely on answers and quotes as evidence from participants. The answers and quotes from the participants are their subjective experiences and, therefore, will lead to knowledge of knowledge in relation to the participants' experiences as parents of children with autism.

**Axiological assumption.** The researcher, being a special needs teacher and an advocate for people with disabilities, feels it is important to spread awareness about the struggles of families who have members with impairments, especially autism. More people should understand what these families are going through and lessen the social stigma. They deserve more respect, and society has to develop helpful services that address the needs of both the parents and the child. It is vital for anyone affiliated with the special education and mental

health profession, such as the researcher, to also see behind the scenes of the family dynamics, mostly because they are part of the professional team for these kids. Families need them, and they should know how to handle and address their needs.

**Methodological assumption.** Qualitative research procedures or methodology are characterized as inductive, emerging, and shaped by the researcher's experience in collecting and analyzing the data (Creswell & Creswell, 2017). To gain better insight from the lived experiences of parents of children with autism during the pandemic, where face-to-face interaction is not allowed, the researcher followed the qualitative methodology, which is inductive. Modification of research questions may happen in the middle of the study. The researcher has followed certain data analysis procedures to gain deep knowledge about parenting children with special needs.

**Participants.** In the selection of the participants of this study, a purposive sampling procedure was used. The concept of purposeful sampling is used in qualitative research. This means that the inquirer selects individuals and sites for study because they can purposefully inform an understanding of the research problem and central phenomenon in the study (Creswell & Creswell, 2017). The researcher selected parents of children with autism as the participants since these parents can give information and articulate their lived experiences as parents of children with autism. Snowball sampling was also done to complete the number of participants and have actual identification.

In addition, the sample size in qualitative research is not only to study a few sites or individuals but also to collect extensive detail about each site or individual studied. Qualitative research intends not to generalize the information (except in some forms of case study research) but to elucidate the particular and the specific (Creswell & Poth, 2016). Dukes (1984) as cited in Creswell and Creswell (2017), recommends 3 – 10 subjects for phenomenology. This study included 5 participants.

Inclusion criteria for the parent-participants include the following: (a) the parents should be parents to adolescents to emerging adults affected by autism, (b) the children with autism have studied or are still studying in either an inclusive education program, mainstreamed program, or not exclusive school for special education, (c) the parents should be biological parents, (d) the parents should be working parents, and (e) the parents should be at least 35 years old to 60 years old.

**Research instrument.** A qualitative interview was used in the collection of data. The in-depth interview in this study extracted the essence of the phenomenon (Creswell & Poth, 2016). The researcher used unstructured, generally open-ended, in-depth interviews to obtain detailed and in-depth information from the participants using their own words regarding their lived experiences as parents of children with autism to confirm the phenomenon. Phenomenological studies rely primarily on interviews as data sources (Creswell & Poth, 2016).

As Creswell and Creswell (2017) suggested, the researcher planned an interview protocol. The interview protocol was two pages in length. There were spaces between the questions for the interviewer to write short notes and quotes in case the audio-recording device did not work. The total number of questions was between 5 and 10, although no precise number can be given. It was prepared before the interview and used consistently in all interviews. It was helpful for the interviewer to memorize the questions so that he or she did not appear to be simply reading the interview protocol. The interview protocol consisted of several important components. These are basic information about the interview, an introduction, the interview content questions with probes, and closing instructions.

**Data collection procedure.** After the panel members approved the proposal paper, permission was obtained from the parents for this qualitative study. Before the interview, the already identified participants were sent a cover letter, an informed consent form, and data privacy through email and messages on social media. They were notified ahead of time of possible questions. After the interview, the participants were informed how long the data would be disposed of.

When rapport was established, the researcher conducted individual parent interviews virtually on the agreed date and time. The researcher asked permission from the participants for a recorded virtual interview. The parents were encouraged to express themselves freely and tell their experiences in their own words. Probing questions and observing the non-verbal language of the parents were noted by the researcher. The psychosocial intervention was given to the participants. They were asked how they felt during the interview and if they were okay to continue. They were asked if there was anything the researcher could do if they did not feel comfortable with the interview anymore. Each interview lasted for about an hour. At the end of each interview, the researcher reminded the participants of the need for a second or third interview until the level of data saturation was reached, as determined by the researcher. They were asked if there was anything the researcher could do so it could be included in the feedback session.

The researcher observed bracketing throughout the interviews. All participants were allowed to say their opinions uninterrupted, and the researcher suggested no misleading statements to manipulate the result of the interviews. Her opinions as an experienced special needs teacher were not infused in the results, nor were important details taken out to taint the findings of the study.

The researcher conducted a debriefing session with the parents after the research study. The researcher provided psychosocial intervention in case the parents needed one. Transcriptions of the interview sessions were followed. Moreover, the researcher gave the parents a token of appreciation as an expression of gratitude.

At the end of the study, the researcher deleted recorded interviews and other obtained data for ethical purposes.

**Data analysis procedure.** The researcher has utilized thematic analysis using the Colaizzi process for phenomenological data analysis. The accurate application of Colaizzi's process of descriptive phenomenology provided an exhaustive description of the lived experiences of the parents of children with autism. The following steps represented the Colaizzi process for phenomenological data analysis.

Each transcript was read and re-read to obtain a general sense of the whole content. Significant statements pertaining to the phenomenon under study were extracted for each transcript. These statements were recorded on a separate sheet noting their pages and line numbers. Meanings were formulated from these significant statements. The formulated meanings were sorted into categories, clusters of themes, and themes. The findings of the study were integrated into an exhaustive description of the phenomenon under study. The fundamental structure of the phenomenon was described. Finally, validation of the findings was sought from the research participants to compare the researcher's descriptive results with their experiences.

**Data trustworthiness.** To show that the data analysis was conducted precisely, consistently, and comprehensively, the researcher determined the trustworthiness of the analysis by using the criteria set by Lincoln and Guba (1985) as cited in Nowell et al. (2017), which are the criteria of credibility, transferability, dependability, and confirmability.

Trustworthiness is how the researcher can show that the study is valid and reliable (Lincoln & Guba, 1985 cited in Nowell et al., 2017).

**Credibility.** This criterion refers to the truth of the data or the participant's view and the interpretation and representation of the researcher (Polit & Beck, 2012). The participants were oriented to give accurate and concrete information, while the researcher gave assurance of confidentiality. The probing questions let the participants elaborate on their experiences parenting a child with autism. Member checking was applied in the study to ensure the truthfulness of the transcripts.

**Transferability.** Transferability refers to results that can be used in another setting. It provides evidence that the research study's findings could apply to other contexts, situations, times, and populations (Lincoln & Guba, 1985 cited in Nowell et al., 2017). This is achieved by providing sufficient information on the information and research context to enable the reader to assess the findings' capability of being "fit" or "transferable". The researcher has provided rich descriptive data, methods, procedures, and interview transcriptions.

**Dependability.** This refers to the consistency of the researcher in adhering to the steps in the research process (Lincoln & Guba, 1985 cited in Nowell et al., 2017). In this study, the researcher ensured the research process was rational, traceable, and well-documented. This was demonstrated by keeping all recorded data, like transcriptions and recorded interview videos, until no further editing existed. The researcher followed and observed the van Kaam method in analyzing the data to ensure the stability of the findings.

**Confirmability.** Confirmability is concerned with the findings being derived from the data. The researcher ensured that the interpretations were not based on subjectivity but were grounded on the data. In this study, the researcher showed how interpretations and conclusions emerged by responsibly securing all notes on decisions made during the process, including reflective thoughts, research materials, and other important details. The data were further validated through the audit trail performed by two external auditors. Their comments and suggestions were considered in finalizing this research, such as revising and simplifying the themes and aligning the statements to the themes.

**Ethical considerations.** The researcher adhered to the following elements of research ethics to respect the participants involved in this study. These elements are based on the Philippine experience in the conduct of research ethics review.

**Social value.** The results of this study are expected to contribute to a better understanding of the lived experiences of parents of children with autism and the promotion of the well-being of these parents and their families and communities. The research design, method, and data collection in this study can gather information relevant to the purpose of the study. Appropriate dissemination of the study results is also considered as this is significant to achieve the social value of this research. This study will be available for those who want to know more about it, like school administrators, teachers, parents, students, and even future researchers. Mental health professionals can also utilize this study to help them understand the family dynamics of their clients who have children with disabilities and know how to better counsel them.

**Informed consent.** Informed consent is a decision of a competent potential participant to be involved in research after receiving and understanding relevant information, without having been subjected to coercion, undue influence, or inducement (Philippine Health Research Ethics Board, 2017).

Relevant information about the study was presented to the participants before the start of the study, and they respected their responses. The participants were told what they would go

through and what questions would be asked. This was a written document sent via a Google form. The participants showed willingness and agreed to participate in this study. The letter stated that their participation is voluntary, and in case they feel threatened and uncomfortable in the middle of the study, they have the right to withdraw as a participant.

**Vulnerability of the research participants.** The participants were fully consensual adults but may feel anxious during the interview if asked to narrate their sensitive experiences with the people around them connected to raising their children with special needs. None of the participants became vulnerable and uncomfortable throughout the interviews but even expounded more on their experiences. To address the possibility of vulnerability, the researcher informed the participants that there were no right or wrong answers in answering the questionnaires, and their responses will not affect the study nor put them in the spot to be judged. The participants were encouraged to answer the statements honestly by ensuring that only the researcher could access them and be utilized for a good purpose.

**Risk and benefits.** The research was carefully analyzed and approved by the ethics committee. The participants were interviewed three times, and they may have been triggered along the way and may have some anxiety and stress levels, but they had the freedom to back out from the study if they wanted to. Whenever they got emotional during the session, the researcher would ask them if they still wanted to continue or skip the question. They were also asked if they wanted the part omitted in the transcription and only the information they felt comfortable sharing would be included. They still wanted to continue, and the researcher thanked them every time. Since everything was done online, there were no physical threats to the researcher or the participant. This research study was justified since the parents of children with autism can benefit from the research.

**Privacy and confidentiality of information.** Before and during the research study, the identity of all respondents was held confidential, and all forms answered by the respondents were deleted from the system. No names will be mentioned in the research paper. The storage of all the data was stored in the researcher's private files, which no one can access since it has passwords and all of them are named under a pseudo name. All data collected and stored during the study will be disposed of or removed from the system as soon as the research is published, which will take a year after their interview.

**Justice.** Purposive and snowball sampling were used in the fair selection of the participants. To have fairness with the participants for this study, their needs always came first before the study. They were free to speak or request privately with the researcher. They were given the liberty of how they wanted to be interviewed, and they had access to the writings of the researcher about their interview. They could agree or disagree with questions if they felt uncomfortable with them. Regardless of their vulnerability, they can benefit from this study, and their participation was very much appreciated. They were sent a token at the end of this study to show gratitude for their involvement and willingness in the study, and no reimbursement was given since they did not pay for anything during the interviews.

**Transparency.** Transparency promotes confidence in research studies, even when privacy and anonymity need to be observed. The researcher observed transparency about the aspects of her study that may have impacted the participants' rights, health, and safety. Everything about the study was disclosed; therefore, there was no conflict of interest. The researcher ensured that the study would be published in a reputable journal to assure the public that the researcher was committed to this study's truthful and honest conduct.

**Qualification of the researcher.** The researcher of this study assures the public that she has the correct qualifications and credentials to do this study at the doctorate level. The

researcher is a licensed professional teacher who is also a professor at the tertiary level of a private catholic school. She has earned her Master's Degree in Education, majoring in Special Education, and has gained 15 years of experience in teaching. She is the appointed program head in the College of Education, an adviser in some student organizations, an adviser of general education and special education majors, and the community outreach coordinator in her department.

The researcher is committed to the ethical practice of her profession and continues to learn more from other short courses, seminars, and workshops for her professional growth. She is a dedicated advocate for special needs children. She continues to teach subjects in the College of Education about inclusivity, special education, and how to address diversity in schools, at home, and in the community.

**Adequacy of facilities.** Since the educational landscape has shifted to online classes, the researcher saw no need for physical facilities. However, online platforms were needed, and RDO and library resources were utilized in this study. The researcher assured that she was skilled with the online platform, and participants could easily access meeting links; hence, data gathering was facilitated without problems. The researcher was also equipped with devices and materials necessary to complete this study, like a laptop, bond paper, ink, printer, and other resources. The researcher was also mindful of the availability of gadgets of the participants. The researcher did not require high-end specifications for the parents to answer the interview.

**Community involvement.** The primary stakeholders involved in this study are the administrators of Recollect and Augustinian schools. Their influence and position will help promote and aid in advancing mental health for parents of typical and atypical children by advocating for children with special needs. They can be very influential in supporting education for inclusivity and special education to students and the community. Second, the teachers teach the concept of special education and inclusion to children and the parents of the school.

Third, the parents who raise the children of today's generation will be very important in positive advocacy for society. They are one of the major keys and forefront people in giving normalcy in the world of diversity in today's youth and educators. They can show that raising different children still gives fulfillment as any normal parent in society does, and there is always joy in raising children with disabilities. With their example of love and positivity, they can take away the stigma of society and be parents of children with special needs who may feel helpless when dealing with and raising these exceptional children. Lastly, the community can support and advocate these unique individuals' rights by normalizing them through inclusion and giving their parents special privileges in a public setting.

## **Chapter II**

### **RESULTS AND DISCUSSION**

#### **Participants**

**Susie** is 60 years old and raised three children with her husband. She has three biological children, and her son, who is 30 years old, has autism. She resides in Bacolod City with her family. Her other children, who are also professionals, help her manage their brother under the spectrum. Her son was enrolled in special education schools. However, he was never under the inclusion program and has to be supervised by family members when out in public, but his behavior is quite manageable. She and her husband are both working in the city. When we had our interviews, she was between clients' schedules and had to squeeze in one hour for our online interview. She has shared about her expertise in different professions and her life at home, especially raising a son with autism.

During our interviews, her son with autism would barge in and ask random things, so she had to repeatedly remind him to stay outside because she was still working. Obediently he would, but sometimes would go back again and ask random things. Susie unreluctantly agreed to be part of this study and was very prompt in giving her a schedule for the interview. She is always very generous with her skills, time, and knowledge and is generally a happy person who would not make you feel uneasy in her presence. She knows this study will benefit other parents who, like her, are just starting to raise a child with autism. She said the researcher could call anytime again or set another appointment if she needed anything related to work, my studies, or anything of her concern.

**Alora** is 38 and was referred by the researcher's thesis advisee from another university. Like her adviser, she is also a special needs teacher and has met a lot of wonderful and strong parents in school. One of them is Aura, and she fits perfectly under the scope of this study and her son with autism is in his late teens. She was very successful in Manila and landed a job that is the ultimate dream workplace of everyone in Manila. However, she transferred back to Bacolod City over a decade ago because of circumstances in raising her son and her spouse. After she separated from her husband, she thought it was best to raise her two kids in the province, where she could get home on time and make it easier for her to be involved in therapies and other services for her son. Eventually, they sorted things out, became good friends again with him, and he co-parents from a distance as much as he can.

As soon as the researcher sent her a message, she agreed to be part of the study right away, and the same week she had an interview with the researcher for more than one hour and did another via Zoom after a few weeks. A doting and hands-on mother, she did not hesitate to return to the province and start from the bottom again because raising her children right is her top priority. She has two children, and her second child, who is in his late teens, has autism. Alora was very genuine during the interview and generous with her insights. She got emotional a few times, recalling her experiences as a mother to a child with autism. However, it only showed her as a brave, resilient, steadfast person and an undefeated mother. Our interviews had to be on hold every now and then because she needed to get back to her son and prompt him on things he would do. Sometimes she would either remind him or prevent him from doing something that might hurt him or destroy things inside the house. After all her struggles in changing careers, she is settled and successfully manages the team she created.

**Wella** is the third participant in this study in her late 40s and resides in Bacolod City. She was referred to the researcher by another professor who knows about her family. The researcher messaged her via social media and asked if she could be a participant in the study,

and she agreed without hesitation. She has a teenage daughter and a 17-year-old son diagnosed with autism. The first interview happened in the same week, and she was very generous in sharing her life experiences, expounding in detail what she has done and gone through. Wella is a secretary of a popular doctor here in Bacolod, and she and her kids reside with her parents in Mansilingan. She became a widow a few years ago and is a hands-on mom, especially to her son with autism. She is familiar with a lot of terms and practices in special education.

During her interviews with the researcher, she was always smiling and left out no questions given to her. Now and then, she controls her emotions, but it only shows her as a very brave woman who never gives up on life's struggles. Her goal was to let her son attend an inclusive school because he is highly functioning and musically talented. Due to social stigma and discrimination in an inclusive school, she witnessed many injustices done to her son many times. She opted to pull out her son from that environment because it made him behave badly and get blamed for everything. Despite her reports, the school did not protect the child enough from other students and adults. Now she and her son are happier in another school, and she worries less when not around him. There were some very important details that she did not mention during our interviews because her family was around and could not say them, so she messaged them instead privately to the researcher. She takes pride in her children's talents; each has a specialty. The son with autism can sing very well. You can see him sing like a pro in malls and school programs. Her daughter is a great artist, too, and Wella takes pride in showing the researcher pictures and videos of their achievements. Looking at her kids now, she realizes all her efforts and sacrifices have paid off.

**Jessie** is the fourth participant in this study. She and her husband have two sons, the eldest is 20 years old, and the younger, 17 years old, has autism. They reside in Bacolod City, but their eldest son attends college elsewhere. Her son with autism used to be a student of the researcher, so she and the researcher are acquainted already. She immediately agreed to participate in this study and squeezed in schedules for the interviews between her very busy routine. She has two professions. She is a licensed nurse, but now she and her husband are well-known architects in the city. Her son, who has autism, is high functioning, and he was in an inclusive class for most of his school years because he could cope with the demands of school. What worries Jessie the most is developing her son's social skills.

She shares how she had to work on making her son come out of his shell and interact more with others, such as inviting random kids into their house and giving them goodies to play with him. She wants her son to be active in many after-school activities, such as boy scout membership, learning to play different musical instruments, and joining recitals. Despite her demanding schedule, raising her son right is her top priority. She is a full-time mom and architect, so her schedule is very tight, but she still agreed to be part of this study. Interviews with her were between her lunch breaks and after meetings. She was very generous in sharing her experiences and was a little emotional occasionally, recalling them. In one interview, she was off camera because she was in her office, yet she was very responsive to all the questions and expounded well on them. She also messages some information about her experiences even after the interviews.

**Helen** is the fifth participant in this study. She is 45 years old and has two sons. The eldest is 21, while the younger is 19, and both have autism. She is a single mom but remains on good terms with her ex-husband. She resides here in Bacolod City, but she owns a restaurant in another town and caters to known customers occasionally. The interviews with her were all via MS Teams at night after her hectic schedule running the family business. She immediately agreed to be part of the study and was very generous to share her experiences raising her sons

with autism. Her struggles were heartfelt, and she got a little emotional every so often recalling her experiences, sad, hopeless, hopeful, difficult, triumphant, fulfilled, etc. They all showed her resilience and willpower, never allowing her to be defeated by whatever struggles she faced.

During the interview, her sons got curious and would intervene by asking whom she was talking with and wanting to join. This a trait not typically seen among children with autism, but it shows how hard she trained them to be polite and as social as they can. There were moments when she had to expound on what the questions meant, and all three depict a happy and contented family. More serious questions and experiences were exchanged between her and the researcher once her sons left. The interviews were done as soon as she finished her day's work, fixed up, and closed her restaurant. She was in her garden, cheerfully opened her life to the researcher, and gave details when asked further. During the next interview, she had to stay inside her room and speak to the researcher privately because she did not want her sons to hear some sensitive topics, such as her struggles with her husband. At one point, her eldest son overheard the conversation about his dad, so he went inside the room and said an incident about him. Ms. Helen explained his son's incident briefly, but after a short while, the son left, and the interview resumed.

### **Thematic Insights**

Three central themes were derived from the interviews conducted with 5 participants who fit the criteria of this study and gave a similar pattern of experiences in raising children with autism until adulthood.

#### **Theme 1: Insights on Parenting of Children with Autism in their Adolescence**

- A. Parents May Initially be in Denial
- B. No Option but to Accept Their Child's Diagnosis and Learn More About It
- C. The Child May Add More Struggle/ Conflict in the Marital Relationship
- D. Accepting Differs Among Parents and It is Always Challenging
- E. A Constant Educator: There is a Need to Teach Them Anything to Equip Them with Life Skills

#### **Theme 2: Difficulties and Struggles of Parenting a Child with Autism**

- A. Parents Face a Variety of Overwhelming Challenging Behaviors
- B. Caregiver Embarrassment and Exhaustion on Being Hands-On Parents
- C. Maximum Patience and Tolerance are Exerted
- D. Facing Different Types of Social Stigmas
- E. Having Incessant Worries and Concerns About the Future
- F. Facing Inevitable Financial Strains
- G. Entrusting the Child to Others is a Problem

#### **Theme 3: Seeing the Silver Lining in Being Parents to a Child with Autism**

- A. Seeing Parenting Efforts Paying Off
- B. Parents Experience Genuine Love
- C. Parents Develop Resilience and Become Braver in Life's Trials
- D. Receiving Blessings in Many Forms
- E. Forgoing Personal Career Goals and Gaining Valuable Life Lessons

#### **Theme 1: Insights on Parenting of Children with Autism in their Adolescence**

Parents willingly and generously shared their thoughts on being parents to a child under the spectrum from the first moment they were handed the diagnosis to their present life with their child. They talked about their first reaction and how they had processed it, which was

difficult. They also spoke about how it had affected their married life and the rough road with spouses who had different opinions about the matter and the plans they initially laid out for their child. Finally, their current view of still being the sole caregiver to their child to this day.

### ***Parents May Initially Be in Denial***

Denial is refusing to acknowledge that your child has a disability. In trying to understand what parents have been told about their children, some struggle with the news and do not know what to do. Reactions and words may not be the same for all parents upon hearing the news about their child, but all these responses expose the fact that they cannot initially accept the reality. Hearing about your child having a handicap from a doctor is never easy, and no parent would ever wish it on their child, and it comes with many emotions. In the different stages of grief, even the first stage is denial because, just like in this case, no one is ever ready to hear it. Even as one participant puts it, another participant had another way of showing her denial upon hearing the devastating news. Like a basic human instinct, when bad news is hurled at you, one unconsciously blocks it off and thinks they can find a remedy. Maybe, with a chance of luck, there is a cure for their child. Even after they hear the news correctly, they stay in denial with the hope that their child will get better and refuse to categorize their child yet with any disability.

*“sang una sg wala pa na diagnose, indi pa namon ma accept but when the doctor said amo na ani, waay na. Actually, I cried sa atubangan ni Doc X. May chansang pani ayhan nga matadlong ni sila? Amo gid na bala. Kay, you always have hope eh”* [Before he was diagnosed, we could not accept it initially, but when the doctor told us this was it, I lost it. I actually cried in front of Doctor X. Is there a chance for us to fix this doc? Because you always have hope.] (Helen, personal communication, February 23, 2022, lines 411-415)

*“Nang siguro ara guid man na sa parents’ initial reaction guro bala nga daw may denial daw indi dayon mag sink in ng autism ni siya or base may ara lang guid siya nga amo na”* [Maybe it really within parents, initially, parents’ reaction will be in denial and the possibility of your child having autism will not sink it right away nor will they think the child has it] (Wella, personal communication February 10, 2022, lines 80-82)

*“Uhhh actually for my kids I’m treating them as regular kids na eh. But before ano different ang approach ko eh kay syempre sang una2 pa lang nga pagkabalo ko ano na eh daw indi ko pa ma accept especially nga duwa gid sila. Pero eventually as time goes by, daw nakita ko nga there’s a great improvement daw ka ok naman. Daw ka amo na ya te subong nga, this is who they are. Wala nko ya care kung ano ang sa gina hambal sang iban.”* [Actually I treat my kids as regular children. I had a different approach back then when I first heard about it and it was hard to accept it especially since 2 of the kids were diagnosed. Eventually, as time goes by, I saw great improvement and they seemed ok. It seems like that and now this is really who they are. I don’t care anymore what others say] (Helen, personal communication, Feb. 23, 2022, lines 22-26)

*“Oo, eventually. Indi man guid super late pero eventually na inchindihan ya man. Wala man siya kabalo sang amo na, wala man ta kabalo kay wala man guid ya sang una mga Google-Google na ya nga ma’Google ka sang Autism* [Yes eventually. It was not super late, but he eventually understood the situation. He had no knowledge about it before because it wasn’t very known to us, and we could not google about autism] (Jessie, personal communication, April 1, 2022, lines 126-128)

*“ Una daw na ’confue lang kami bala. Ay ano lang ni guro... normal lang sa kids nga hyper. Amo lang na permi na hambal nila nga, “Hyper lang na. amo gid na kay lalaki siya.” [At first, we were just confused. We thought it was just normal for kids to be hyper. They also tell us it is normal for him to be hyper because he is a boy] (Helen, personal communication, April 6, 2022, lines 14-17)*

### ***No Option but to Accept Their Child’s Diagnosis and Learn More About It***

Another way for parents to accept their child's condition is knowing they have no other way to deal with it but to simply accept it. Upon receiving the devastating news, they know they have no time to waste thinking about the situation. The sooner they accept it, the more they can clarify what they must do. Taking in the news is a very powerful moment for parents and a significant turning point for them, and this is never a happy moment for any parent in this situation. After being overwhelmed with emotions, they eventually acknowledge their reactions, snap back to reality and start moving forward. They know they are the main caregiver, and everything is in their hands now. They have to be a parent and start advocating for their child. Ultimately and instinctively, they feel a sense of acceptance; this is how they make sensible plans and decisions.

Denial is essentially human and is a defensive mechanism that keeps us from getting too close to pain. We need denial when we are not strong enough internally or when we do not have enough support to deal with a painful situation (Naseef, 2015). According to one participant:

*“ But one thing I realized is that you must have the knowledge of autism and accept things as they are. “ (Susie, personal communication February 1, 2022, lines 17-19)*

*“\_It was a long road to acceptance but I have no choice. You just accept! Once there is acceptance you let go and let God do things” (Susie, personal communication, February. 1,2022, lines 12-13)*

*“ Pero I said I have to stop thinking about it and e accept nalang gd and wala cure. Himuon nalang tanan to help him improve” [But I told myself to stop thinking about and accept that there is no cure. I will just do everything to help him improve] (Alora, personal communication, February 4, 2022, lines 358-359)*

*“ indi na siya mayo negative kay ang acceptance bala ara na. Once ang acceptance ara na, ang negative na ya, naga-ano na na... ga pahigad na na siya. “ [It is not going to be negative when there is acceptance. Once there is acceptance, the negative disappears.] (Wella, personal communication, February 10, 2022, lines 110-113)*

*“ So gin’face ko guid ya ang ano ya... ang life nga amo na eh. Nga kinanglan maging maisog ko kay ti syempre five years old pa lang siya daw peak guid na ya sang hyperactivity ya ya kag tanan nga tantrums.” [ So I had to face this kind of life. I have to be brave, especially when he was five years old, which was the peak of his hyperactivity and all sorts of tantrums] (Helen, personal communication, February 23, 2022, lines 120-122)*

*“ Kay ngaa, kung you will never accept things that your kid is that. You will never help your kid. Amo guid na ang akon na’ano. Indi mo guid 17ay a ma’help ang kids mo if you yourself denies that there is a problem. Do not consider it as a problem, just a challenge” [ If you never accept the condition of your kid, you will never be able to help them too. You will not be able to help your kid if you deny the reality of their situation. Do not think of it as a problem but only as a challenge] (Helen, personal communication, February 23, 2022, lines 248-251)*

“Daw ka, daw ka bug-at sa ila siguro kay ikaw ya as a mother nakita mo that you don't Have a choice but to accept, sa ilaw daw nabudlayan sila guro mag accept miss. Wala ka choice, sino ma accept sa bata mo? But you.” [It is heavy for others to accept, but if you are the mother, you do not have any other choice but to accept. It may be hard for them to accept reality, but you must accept your child. Who else is there to accept your child but you] (Alora, personal communication, March 31, 2022, lines 121-126)

Gina'remind ko guid na nga, "Hen, nga lain ni ang world ta. Lain na ang world sang iban nga parents. They might be enjoying that, and you cannot have that." Te daw amo lang na, gina-accept ko na lang na nga amo na lang na actually kag gina-accept ko na lang nga amo na. [I must keep reminding myself, "Hen, your world is already different. The world of other parents is different from yours. You cannot have what they are enjoying. So that is it, I just accept my fate] (Helen, personal communication, April 6, 2022, lines 83-87)

### ***The Child May Add More Struggle/ Conflict in the Marital Relationship***

Another sub-theme under the process of acceptance experienced by all participants was the timeline of acceptance of the couple about the diagnosis. It goes without saying that it takes a village to raise a child, let alone a child with autism. For couples sharing this responsibility, there are many things to argue about along the way, such as child-rearing ways, types of treatments they see fit, and many more factors. On the other hand, going through some issues as a team can lead to a stronger bond. The real strain in the relationship starts when the news about their child having autism is given, and both have dissimilar opinions about it. Studies have shown that parenting a child with autism increases marital conflicts and diminishes marital love (Chan & Leung, 2020).

The result has shown that having a child with autism had high levels of parenting stress and co-parenting conflicts. Also, when one parent is not in the same boat as his/her spouse, a huge rift will draw a line between them. In this study, 80% of the participants said the wife accepted the situation faster and had the presence of mind to spearhead plans for the child right away. The interview revealed that having lower involvement, the mothers are the main caregivers, and they make the major decisions for the child. As pointed out by participant number 5, even her husband lacked emotional support, empathy, and other fatherly duties to the point that she would rather drive him away. From this observation, you can see he seemed withdrawn in his obligations to this child because his acceptance was delayed compared to his wife.

“Sang two years old siya kaky that time may ubra ko mo, mayo man ubra sang daddy ya. However, ang daddy ya te kabata pagid bala sang amo tu nga time, ang response ya sang Nabal-an ya nga may autism si Y is totally different from me, ako nag focus ko sa ila. Siya daw indi ya bala mabaton nga ang bata ya amo na, daw amo na bala miss? So napa barkada siya, wala ya kami gina updan therapy so nagka separate kami nga nag ginamo gd kami. “ [When he was 2 years I had a good job and so did his dad. However, since his dad was too young during that time, his response to the autism diagnosis was different from mine so I had to keep my focus on my kids. He couldn't accept his son was like that, it was like that miss. He was out all the time with his friends and he was always absent even during his son's therapy and eventually the situation got worse and we had to separate.](Alora, personal communication, February 4, 2022, lines 438-443)

“I'm a single mom. Gin'bayaan kami sang papa nila. (I'm a single mom. Their dad left us) So I have to do it” (Helen, personal communication, February 23, 2022, line 164)

“Imagina pa gd bala ms ho. Amo na na problema ko sa kabataan, duwa ka special kids. Nag tinunto pa bana ko” [Imagine this ms, this was my problem with my kids, both of them are special

yet my husband still fooled around] (Helen, personal communication, February 23, 2022, lines 300-301)

*“ Parang lain ag akon husband’s way to accept kay te ano siya miss mo, ma inchindihan ko man siya Because he was too young um, nagpakasal kami I think he was only 20.”* [My husband had a different way of accepting the situation, but I understood why he was like that. He was too young, and we got married when he was only 20 years old] (Alora, personal communication March 31, 2022, lines 80-81)

*“ indi ko ka inchindi ngaa wala kadi sa balay, eh kinanglan-kinanglan Ka namun, daw amo na bala miss, so amo na nga iya nga... ang akon ya hambal ko bahala Kada mag barkada ka ako ya ma focus ko sa mga bata ko so indi nakami okay nga duwa”* [I could not understand why you are not here at home when we really needed you, it was like that ms. So that was him but I said, you are on your own, it is up to you if you want to be with your friends but I will focus on my children. Both of us were not ok with each other.] (Alora, personal communication, March 31, 2022, lines 93-95)

*“ Te amo na panulok ko sa ila daddy sang una mo daw lain ang iya nga pag accept sang Things kay nagsugod sang satu, daw wala na siya naga ano sa balay, daw amo na bala Napa barkada sa, siguro...” “ Kay ang tatay usually mam ano eh daw ma pride, lalaki right?”* [Well that’s how I saw their dad before, his acceptance of the new reality was different and from then on he was hardly at home, it was something like that. He was with his friends, and usually fathers have pride, men are right] (Alora, personal communication, March 31, 2022, lines 111-113, 119)

*“ Ah... delay ang acceptance ni Jon. Ako ya mas ahead guid ko 'to ya. Ang bana ko ya, ti... basta ako ya tutok na tutok guid ko ya kay J. Grabe guid ya ang bana ko ya, ti... basta ako ya tutok na tutok guid ko ya kay J. Grabe guid ya ang acceptance ko dayun. Siya ya medyo na late, pero ara man.”* [Ah, Jon’s acceptance was delayed while mine was ahead. My husband was well... but I was focused on J. My husband was different then, but I just focused on J because I had really accepted the reality. His was delayed, but eventually, he did] (Jessie, personal communication, April 1, 2022, lines 122-124)

*““Sige na, try to hit my son again and I will kill you,” nag-amo na ko na ya, nag’lab-ot na ko sa time nga amo na, I’m very patient eh. Nag’focus ko sa iya, sa kabataan. Daw indi sa bala guro ka accept haw.”* [Ok, try to hit my son again and I will kill you. It reached to a point that I had to do that and I’m a very patient person. I focused on his children and it seemed like he could not accept them] (Helen, personal communication, April 6, 2022, lines 548-550)

*No. Mas dasig na accept sg husband ko na accept sang sa akon.”* [No. My husband accepted it faster than I did] (Susie, personal communication, March 21, 2022, line 111)

### **Accepting Differs Among Parents and It is Always Challenging**

Although receiving your child's diagnosis can give a lot of clarity and confirmation for what one has been suspecting, it also triggers many negative emotions in parents. Learning to accept and trying to adjust to it does not happen overnight. They take time, and parents go through challenging times to accept it. This stage of acceptance commonly happens to all parents. This usually happens because, from the very beginning, when parents bring their children into this world, they only have good intentions for their children. They have a good vision for their future, and they, too, want to become the best parents as much as possible. Receiving news about their child being diagnosed with autism can cloud their good foresight, and the constant worries and fears linger in them. This is why it is generally challenging for parents to accept their child's condition. The participants in this study were a bit emotional

during the interview, recalling their own experiences when they received their news and what they had to do after. They went through a very important process before they saw the light at the end of the tunnel.

*" Medjo, ano ka nalang da... medjo... ginhawa tudo, ginhawa dalom. Wala ta may mahimo" [So Just breathe in deep. We cannot do anything about it ] (Alora, personal communication February 4, 2022,, line 129)*

*" So parang maminsar ka man bala nga, sige lang Lord may plano ka, may plano ka, amo nalang na gina kwan ko. So amo na sya for the negative nga indi ma sya magigin negative if you learn to really accept bala, nga there are times nga ma give up ka na gd." [So you will think and say, that is fine, Lord, I know you have a plan, but you know. That is it for the negative side, but it really will not be negative anymore once you accept it, even if there are times you feel like giving up] (Alora, personal communication February. 4, 2022, lines 175-178)*

*" But eventually ikaw mismo nagkabata na amo na it is really difficult especially ang acceptance time bala nga ay amo gd na gale sila ya. Biskan ano mo ka struggle to make them kisa gina deny mo pa sa imo self mo nga they're different. But eventually, as you accept things, dira mo ma realize nga "ay different gale world nila. "You learn to be more patient and accept things." [It is difficult to have a child like that, especially the acceptance, because you realize they are like that. No matter how you struggle, you cannot deny their differences. But once you learn to accept, you will realize they have a different world, and you learn to be more patient and accepting] (Helen, personal communication, February. 23, 2022, lines 34-38)*

*" Right away... Right away guid ko ya. May acceptance guid ko ya right away kay critical guid na sa ya katama sa development sang bata. Once accept mo na siya, open ka sa mga suggestions, so makabulig siya sa bata. Huo kay ang goal ko guid ya Miss, basi palang puwede siya maging regular student." [Right away, I had to have accepted because it is critical in the child's development. Once you have accepted it, you become more open to suggestions that can be helpful for your child. Yes, Ms, I have a goal, and that is the possibility of him being a regular student ] (Jessie, personal communication, April 1, line 76-79)*

*" On the latter part na, indi right away kay ang acceptance is not easy. It took us a while kay we're still hoping nga, "Ahh indi ah, madula lang na sa after a while." [ The acceptance is not immediate and not easy. It took us a while to do it because we hoped it would just go away. ] (Helen, personal communication, April 6, 2022, line 62-63)*

*" Pero I do not think nga daw ka trouble guid for me, or it is really hard for me. I do not take it that way 'cause, I mean, that's our life. It is different from others, but then we have to embrace it. Amo na sila, te sige lang. Kung ano makaya every single time, then let's do it. Daw amo lang na siya" [ I did not think it was such trouble or hard for me. I do not take it that way because, I mean, that is our life. It is different from others, but then we have to embrace it. If they are really like that, then ok. I will make it through every single time, and I will do it. That is it.] (Helen, personal communication, April 6, 2022, line 239-242)*

### ***A Constant Educator: There is a Need to Teach Them Anything to Equip Them with Life Skills***

This theme covers one of the parents' top concerns for their children, which is constantly teaching them independence and practical life skills every moment they get out of their worry that their child should survive when they are no longer around for them in the future. Since one of the biggest concerns of parents for their children with ASD is their future, they teach them

skills that will help them survive and cope on their own once their parents are not around. Parents know that autism, even with therapies, has no cure and is lifelong, so they emphasize the need to plan early for the child's life ahead of him. The need to teach them whatever they need to have a better quality of life happens constantly, and parents have every chance they get to impart these lessons to their children.

Teaching moments happen most unexpectedly and all the time from the parents to their children. These teaching moments done by parents do not have any structure, and it occurs whenever the child and parent are together. Parents are very patient in teaching their kids and have realistic expectations for them. Generally, they cannot break free from the need to teach them, and reinforcing the self-reliant skills happens spontaneously or systematically. Parents in this study have formed strong opinions on this matter, one of the most important things they can bequeath to their children. Often, they ask, can my child do this task without me? I will make him do it again now. Will they know how to say this on their own? I want to see it if he can now. Will he do it right and safely without my guidance? He did not the last time, so I must test him again now. The list of concerns goes on.

Parents of children under the spectrum worry that in the future, their child may most likely not have the freedom to live like other neurotypical children during their adult and adolescent years. The parents know what skills to teach them for independent living later. Just like a building, children with autism need a strong foundation to make it through life and withstand the demands of basic survival, and parents map out that plan for them. They ensure their abilities are enough to make them enjoy life and know how to assert their rights as humans in a suitable environment when they are no longer around.

*"Tapos gina'raise ko guid na ang awareness sa ila. Kay te syempre di ba wala sila judgement sa tanan nga tawo. "Everybody is good," diba amo gid na ang initial nga mindset ang mga bata na, they're innocent eh. Gina'pungko ko guid na sa lamisa. Siling ko, "Pungko. Indi tanan nga tawo they look good, are all good. Not all Muslims are bad. Mga things nga realization sa tuod-tuod nga kabuhi kay indi man fairy tale tanan mo nga pariyos di sa house nga everybody is pleased with them. Indi sila ya siling nga ma'judge sila kay we know them but sa gwa ya no, you can never please anyone. Nga amo na bala, gina'fit ko na sila ya sa reality. Na amo ko gd na sila ya." [I raise their awareness because you know them. They do not judge people. Everybody is good. Isn't that the initial mindset of children because they are innocent? I sit down and explain to them that people may look good, but they are all good. Not all Muslims are bad. They need realizations on so many things in life, and it is not a fairy tale, and everyone here in the house is pleased with them. They do not judge here because we know them, but outside, you can never please anyone. I fit them in reality. I really do that to them. ]Helen, personal communication, February 23, 2022, lines 440-450*

*““Mama when you do have time, can you bring me to Lola Mommy, my mother, may gamay kami to nga canteen lapit sa Graceland bala sa Minoyan. So everytime we visit, gina pa'ano namon sa tiangge, “Ano baklon mo?” Kung pila ang kambyo, i'lista ang sales. Mga amo2 na. Gina pang amo na sila. Para they can have hands-on experience on things.” [Mama when you do have time, can you bring me to Grandma Mommy, my mother? We have a small canteen there near Graceland in Minoyan town. So every time we visit, we make them practice manning the store and ask, "What will you buy?" We check the change they give back and list down the sales. We make them do things like that to have hands-on experience.] (Helen, personal communication, Feb. 23, 2022, lines 181-185)*

*" Para in the future, kung wala ko to defend them. Amo lang na fear ko nga they cannot defend themselves. So if I tell them nga, for example, nga... when we eat out, bilin ko sila nga, "Never talk to strangers." Indi guid na sila ya mag talk. ( And that is, that is in connection with your concern in the future mam? Amo na ang concern mo?) [This is for the future when I am not around anymore to defend them. That is my only fear which is that they cannot defend themselves.*

For example, if we eat out, I leave them and tell them not to talk to strangers. They really will not speak.] (Wella, personal communication, February. 10. 202, lines 452-454)

" *Huo, gina prepare ko sila miss. Amo lang guid na gusto ko nga ma prepare sla sa future. I do not care about their grades. Let's say makadto di ang teacher mahambal nga, "Mam, si amo ni nag nubo sa amo ni. Stephen taas na iya grade. Kay si Stephen is really smart. Tag as tag-as na iya grades, with honors pa na. Siling ko, "I do not care about the grades. What I care about is that they learn from the things they can use in their future. Anyway, grades do not matter eh. Nag honor student man da and all, wala man na ga count sa future. Ang gusto ko lang ya, ma street-wise sila, amo lang guid na - they can defend themselves and feed themselves in the future. Amo lang man na guro worry sang every parent, diba?* [Yes, I really prepare them, miss. That is all I want, to prepare them for their future. I do not care about grades. Let us say Stephen's teachers will come here and tell me his grade got low. Stephen has higher grades. He is really smart. He has high grades and honors. I do not care about grades. What I care about is that they learn from what they can use in the future. Anyway, grades do not matter. With honors and all, that will not count in the future. Anyway, grades do not matter. I think that is every parent's worry] (Helen, personal communication, February 23, 2022, lines 457-465)

*No, ang gina wish ko lang ya nga ma support nila selfnila. That's why I am helping them mag... inang mga practical living bala nga skills.*" [My only wish is for them to be able to support themselves. That is why I am helping them have practical living skills. ] (Helen, personal communication February. 23, 2022, lines 424- 425)

" *Before sang pandemic nag nag, gusto ko guid na sa bala tani I try. Kay may eldest son is asking if he could go to school ning ma jeep lang daw siya. Because I am always tending them back and forth sa school eh di ba. So they said, "Mama, we will just ride the jeepney. It is okay, so you can do your stuff." Siling ko, "I am scared." Ako ya ang scared. Di ba syempre they may meet new people, and this and that and that. Siling ya, "No." Ti sige, we will have a trial, I will give you money, and then this is the money that you have to pay and then, but I follow first the jeepney hahaha siling ko, ride lang kamo ya jeepney, but I will follow the jeepney for me to know hahaha.* [Before the pandemic hit, I wanted to try it. My eldest son asked if he could go to school independently and take public transportation. Since I was the one always bringing them back and forth to school, they said, Mama, we will just ride the jeepney. It is okay, so you can do your stuff," but I said I am scared." I am the scared one. They might meet new people and this and that along the way. He said, "No," and I said, "ok, we will have a trial, I will give you money and use that to pay for your fare, but I will still follow the first jeepney hahaha. Just ride, but I will still follow your jeepney for me to know hahaha.] (Helen, personal communication February 23, 2022, lines 144-151)

*But gina continue ko na ang ila challenge subong nga like we go out. And let us say I will give them a hundred pesos, and you will order. Stay within your budget. Order there in Jollibee. I will let them fall in line, and then I am at the back. Kay gina hands-on ko maam. Even before, grabe na ang struggle ko sa ila* [But I continued their challenge until now like if we go out. And let us say I will give them a hundred pesos, and you will order. Stay within your budget. Order there in Jollibee. I will let them fall in line, and then I am at the back. I will be hands-on with them, Ms. Before, this was my struggle with them]. (Helen, personal communication, February 23, 2022, lines 154-163)

" *Ina balang, anhon mo na ang kwarta, anhon mo na ang ano, kung ang bata mo, indi sila magpati sa imo. Kag ina balang, syempre lifetime mo na sila nga ano mu, lifetime mo na nga i'assist. Te, lifetime man nga may yaya ka? Lifetime man nga may ma'handle sa ila? So wala diba? So as a parent, kinanglan i'prepare mo man sila eh nga indi man sa tanan nga oras, ara ka. So kinanglan, i ano mo guid sila ya, i prepare mo man sila mangin independent* [What will you do with the money if your child is like that, you cannot get them to obey you. And you know, it will be a lifetime of assisting them. So will you be their caregiver for a lifetime? Will there be

someone who will handle them for a lifetime? No, there will not be. So as a parent, you need to prepare them, and it is not every hour that you will be there for them. So you need to guide them so they will be independent later on] (Wella, personal communication, February. 10, 2022, lines 206-210)

*“ chakto ka miss (you are correct miss), in order for your child to develop, you have to be committed to let Him develop or guide him towards that development that you want to achieve.”* (Jessie, personal communication, February. 16, 2022, lines 203-204)

*“ Pero ara gid koya miss galantawa gid koya, did you make your amo na? Can you Understand your lesson? Ako gidya ang iya nga ano ya miss eh, nga teacher te I would like To give up naman para maka concentrate... ma... ma office nako bi amo na, but daw ma ano ka nalang. “ [But I am around to watch over and ask have you done your tasks? Can you understand your lesson? I am his teacher, and I would like to give up on this so I can also concentrate, but when I leave for the office, I still want to] (Jessie, personal communication, February. 16, 2022, lines 111-114)*

*“ Kay I teach them to be very independent guid ya maam. Even before the pandemic.”* (Helen, personal communication, February. 23, 2022, line 140)

*“ Yes ma. We are just gonna lock anyway and not talk to anyone.” Kay my instructions, I always told them never to talk to strangers, never let anyone come in even though they know them without my permission without my knowledge. So gapanawag lang na sila, "Mama, there is a person there oh." Na amo na. I fear leaving them alone. "[So they call me to let me know there is a person there. This is why I fear leaving them alone] Helen, personal communication, February. 23, 2022, lines 131-135*

*“ ang sakon ya perm inga ara sa ulo ko nga dapat maging independent siya bi kay indi ta mapaktan, not all the time, ara ko para sa iya. So kinanglan kabalo guid siya mag ano sa iya nga self, kay te kabudlay [What is always in my head is for them to be independent because we cannot always predict that I will always be there for him. So he really needs to fend for himself because he will have a hard time too] (Wella, personal communication, March 29, 2022, line 122-126)*

*So kung duwa sila, ti dapat may ara pa guid nga mabilin pa guid sa ila. So amo na, preparation guid permi, preparation guid sa ila nga ano... sa life” [So if there are two of them, there should be another one who can be with them. So they should really be prepared always, preparation for their life.] Wella, March 29, 2022, lines 126-130*

*“ ginapa-aware ko sila nga, (I make them aware)"Not people are good. Some may be good to you in front, but others might have bad intentions. Amo na ang difficulties sa ila eh (these are my difficulties with them). Kay because they think that the world is okay. Especially if they are in the house, they are in comfort. Everything is good, okay lang(it is ok), but I always remind them that not everyone is good. You have to reserve things to yourself.” (Helen, personal communication, April 6, 2022, lines 107-114)*

*“ Kung may chance guid ya I have to tell them. Huo kay gusto ko guid na nga ma-aware sila kay when will you do that? Kung indi mo na kaya? I mean, if there is a chance, grab it. Let them know. In simple things, although kis-a malimtan nila but then you keep reminding them. Kay I believe on constant reminders eh” [If there is a chance, I must tell them. Yes, I want to make them aware as much as possible because when else can you do that? When can you not do it anymore? Kung indi mo na kaya? I mean, if there is a chance, grab it. Let them know. In simple situations, although they might forget this, you must keep reminding them. I believe it is necessary to constantly remind them.] (Helen, personal communication, April 6, 2022, lines 151-154)*

*“ It’s a continuous process eh. They are not completely prepared pa sa future. Let’s take that. Inang damo pa sila dapat m’ learn (they still have a lot to learn). So, we have to go through that every single day.” (Helen, personal communication, April 6, 2022, lines 235-237)*

*“ You really have to. Amo gid na dapat pag’treat mo sa ila. Dapat i’treat mo guid sila ya nga daw ka normal lang guid sila ya. And then you have to raise to them ang mga faults kag mga things nga they are not aware of. Hambalon ko na sila, “Indi to puwede nga amhon mo to kay indi na siya puwede sa public ha? Like before ga’ride lang kami sa jeepney.” [ You really have to. You really have to treat them like that. Treat them like they are normal. Then you just have to raise their faults to them and other things they are not yet aware of. I told them, “ You cannot do that next time because that is not allowed in public ok?” For instance, like when were riding in a jeepney] (Helen, personal communication, April 6, 2022, lines 360-365)*

*“ Pero at least they are aware nga indi gale puwede. Nga te kung diri lang sa amon, kung ara lang kami sa amon nga comfort, they can do what they can do. Pero kung ara ka sa publc, indi puwede na kay may ara man sang norm nga kilanlan nila i’follow.” [But at least they are aware that it is not allowed. If they are just here in the comforts of our house, they can do what they can do. But if they are in public they are not allowed to do it because there are norms they have to follow] (Helen, personal communication, April 6, 2022, lines 379-382)*

## **Theme 2: Difficulties and Struggles of Parenting a Child with Autism**

One of the most, if not the most dominant struggles of parents of children with autism is handling a variety of difficult behaviors attached to autism. According to studies, challenging behaviors remain the top concern of parents with children with ASD. More than 40% of them have it, and even if they receive treatments, some difficult behaviors are still present (Edelson, 2022). Parents struggle at home and in public when dealing with these behaviors, which very often attract uncomfortable stares from people. This is a topic that the participants had a lot of unique experiences with and shared generously during the interviews, and it is the most common struggle among them.

### ***Parents Face a Variety of Overwhelming Challenging Behaviors***

One of the many reasons why individuals with autism under different age groups have challenging behaviors is that they have trouble understanding what is going on around them, and they feel overwhelmed. Acting out behavior is not at par with their age because they cannot easily verbalize what they want to say. Parents in this study had their share of difficult situations handling their children when they were acting out. They have tried different strategies to handle them to de-escalate aggressive actions and other unusual behaviors.

Other people often do not mediate when a scene occurs because only parents know how to predict, manage, and reduce this occurrence. They claim that these experiences were tough, overwhelming, and almost traumatic, hence something that other regular parents cannot come close to what they go through regularly. Commonly mentioned challenging behaviors these parents encounter are aggression, property challenges, self-injury, running away, and inappropriate behavior in public.

Globally, families of individuals under the autism spectrum deal with the difficult behaviors of their sibling or child, most especially in public. It is even more difficult to handle them in social places than at home. These acting-out behaviors just surface even if the child has been prompted before leaving. There is no sign that they could possibly have a meltdown when they are taken in public places. They have an unusual sensory system and get overwhelmed by things around them in public, and parents must control them when they have outbursts.

*So amo gd na siya, kung upset siya you have to remain cool. Do not lose your composure. Kay, the more he will be upset and then amo gd na eh. Do not resort to aggression kay subong kanami gd sg iya na behavior ya. “ [So if he is upset, you must remain cool. Do not lose your*

composure, or the more he will be upset, which is what will happen. Do not resort to aggression because now he behaves well.] (Susie, personal communication, February 1, 2022, lines 93-95)

*“Oo as much as possible like upset siya or there is some sort of emergency, or something happened nga daw wala gina expect. Syempre siya ma upset so kung ma upset ka man. The more you will be nervous. So dapat e regulate mo man self mo. Ikaw ya ma calma. Kasi when they become anxious syempre they do not know how to regulate themselves. They can be aggressive. You, you just have to stay calm”* [Yes, as much as possible, like he is upset or there is some sort of emergency or something unexpected happens. So, of course, if he gets upset, you also will. The more you will be nervous. So you also have to regulate yourself. You have to calm down first because if they become anxious, of course, they do not know how to regulate themselves. They can be aggressive. You, you just have to stay calm] (Susie, personal communication, February 1, 2022, lines 106-110)

*“The negative thing kay te especially kung mangakig nako bala, manginit ko kung mag wild si Yohanne, so... ina bala ang indi mo man sya... nang ma akigan mo man sya, ma ano man sya Because nag wild sya. Nang, there are times bala nga makibot ka lang nga ngaa nag react ka Man bala nga gin kigan mo man sya,”* [The negative thing is because especially if I get angry and mad if Yohan becomes wild so I cannot also...if you get mad at him he will also do the same because he became wild. There are times that you catch yourself saying why did I react like that and why did you get mad at him.] (Alora, personal communication, February 4, 2022, lines 146-149)

*“ daw indi na siya namon ma'manage kay daw grabe na guid. Ara na ang biting, screaming... tapos na ang amo na bala, ang ano... kung buy-an mo na siya, daw trumpo... indi mon a siya ea siling nga mabuy-an. Daw puro na lang kamo ya gapos ya nga duwa. Tapos once nga dakpon mo na na siya, gapuson or anhon mo na siya, mangagat na siya. So, na balang... daw ka ano na... gawala na bala daw ikaw man mismo na 'stresss ka na.”* [It seemed like we couldn't manage him anymore because it was really getting worse. There was already biting, screaming... then there are times if we let him go he is like a spinning top...we cannot let him also go and it seems like he is always being constricted and if you catch him, you need to hold him down and he will bite. So it is like...getting out of hand and you get so stressed out.] (Wella, personal communication, February 10, 2022, lines 52-57)

*“ Kumbaga, naagyan... ay grabe . Kung ang struggle lang guro nga naagyan ko, te grabe eh. Galigid na sa ya sa tunga dalan ya. Grabe na sa kay rigid na sa katama. So once lang na ya nga may maano lang na ya sa iya nga panulukan, may naglain, may gusto siya nga wala mo natuman, te mamaoy guid na siya ya.* [So when it comes to experiences...it was extreme. If it is just my struggles in my experiences, well it was really extreme. He was rolling in the middle of the road already. He is so rigid. So once he can sense something different, he didn't get what he wanted then he will really throw a fit] (Wella, personal communication, February 10, 2022, lines 247-252)

*“Sg gamay na sila, mga younger years pa lang, if u are planning to go out lets say b ma lagaw lagaw ka, kung upod mo kabataan mo, ila lang gd nay a tanan. You have to focus everything sa ila lang. indi ka na ya ka siling mangita ka sg blouse mo, mangita ka sg kung ano da. You cant do that. Ila lang guid nay a kay if you lose sight ka lang sa ila, ato na sila sa sinehan ka SM ga linya kay Shrek te daw ka ang danger bala”* [When they were still younger, if you are planning to go out lets say you want to go look around, if you have your kids with you, its really just their time. You just give your focus all to them. You cannot go and choose a blouse or find something. You cant do that. Every moment is for them because if you lose sight of them, they will be everywhere and they end in cinemas lining up for a Shrek movie and it really posts a danger] (Helen, personal communication, February 23, 2022, lines 63-68)

*“ Even, looking back sang younger ages pa sila. Grabe guid ya, difficult gid kaayo. [Even looking back on their younger years, it was really too much. My experience was really difficult.] (Helen, personal communication, February 23, 2022, line 317)*

*“ Siguro ang difficulty amo na eh they are very rigid to routine. They are so structured. Ang Isa ko pa gd ka difficulty ya to be very honest is mag gwa kamo. Baw hostage niya gd ko na. Blackmail niya gd ko na. Mag gwa kamo, you just pray nalang ina balang gina kulbaan ka Sg gina pang ngwa niya kay kadamo sg balayran mo Ma insist gd na siya ya! Although before gina hambalan ko na siya poy no more money poy Ha. Ma oo oo na siya kag pag abot to kwaon niya man nag yapon. Wise man. Kisa Ikaw pa Gina into niya. “[Maybe the most difficult was their rigid routine. They are so structured. Another difficult thing about them is when you go out, it is like they hold you hostage. He blackmails you. When you go out, you just pray, and you get nervous about what he does because you think of the things you will have to pay for. He will really insist! Although beforehand, I already told him we could not pay, I have no more money, Poy ok? He will just agree, but once you get there, he will still get what he wants. He is wise, and he fools you] (Susie, personal communication, February 1, 2022, lines 130-137)*

*there are times gid ang pinaka challenge gid is kung Dal-un siya namun kay ma huy-an kagid. Mahibi siya ya gulpi, ma wild siya ya gulpi. [There are times that the biggest challenge is bringing him out with us because you will be embarrassed. He will suddenly cry and become wild so quickly] (Alora, personal communication, March 31, 2022, lines 213-217)*

*“ wala kami nag ano, nag intervention, sang mga... abi namon, sige lang ah, kaya pa man, kay ti gamay pa mu. Ti sang three years old siya, didto na kami nga nag ano... nag seek help na kami kay indi na masarangan ang iya nga palak kag syempre ikaw man, stressed na stressed ka na kay tanan na lang ya, punggan mo na lang sa iya bala haw.” [ We didn’t take intervention. We thought its ok, we can still do this, well they were still small then. When he turned 3 that was when we sought for help because we couldn’t handle when he resists and of course it is so stressful for you because in everything, you have to hold him down] (Wella, personal communication, March 29, 2022, lines 107-112)*

*“ Another thing is they are emotionally unstable eh. They sometimes really... especially when they were younger. Grabe guid ya ang adjustment ko. There are times nga ma'maoy na sila sa street. I have to control them.” [ I really struggled with adjusting to them. There were times when they would just have a meltdown in the streets, and I have no control over them] (Helen, personal communication, April 6, 2022, lines 171-174)*

### **Caregiver Embarrassment and Exhaustion on Being Hands-On Parents**

Parents of children with autism face different challenges, which are far different from regular parents. Many people would listen and probably agree when these parents explain what they must do for their child, but they would not come very close to genuinely understanding how it has worn them out in different ways. Aside from this, meltdowns and certain autism misbehaviors make them lose face. Bystanders cringe at the sight of them trying to hold down their child. Parents go through many humiliating moments with their children; even if this becomes a regular occurrence, it does not get old.

No matter how they stifle the situation, they cannot escape the shame that comes with it. In this study, 80% of the participants had a lot of cringe-worthy experiences that embarrassed them to the most extreme degree. No matter how much discomfort it gave them and how many stares it elicited from people, they did not escape the situation and dealt with it bravely as best as they could. They are their child's safe zone and creating that zone for them does not let the embarrassment stop them from being protective parents.

In a qualitative study by Yaacob et al. (2021), four themes resulted in the research, and the third one was "psychological distress and stigma". Apart from the many similar challenges, the word "embarrassed" was commonly used among the 21 participants. They considered public tantrums the most challenging of all and said that the perceived opinions in public were far more frustrating than the behavior of the child itself.

*"I am proud of them actually but una una guid mam of course may ara gid ya time na mahuya ka bala when they were younger. Would you believe ma lagaw kami sa SM sugaton ang tren"* [ I am proud of them actually, but of course, mam there was a time I was ashamed when they were younger. Would you believe when we go to SM mall, he would go straight to that moving mini train] (Helen, personal communication Feb. 23, 2022, lines 52-59)

*" Weak eh kay (because)you feel at times when you worry too much. There are times when the Behaviors become difficult, and it also gets on your nerves"* (Susie, personal communication, February 2, 2022, lines 21-22)

*may gusto siya nga wala mo natuman, te mamaoy guid na siya ya, biskan diin pa, so maligid da sa ya sa tunga dalan. Syempre diba, ang initial nga ano sang parents, mahuya or maano" [ He wants something, and when he does not get it, he will really have a meltdown anywhere and would roll in the middle of the road. So, of course, initially, parents will be embarrassed]* (Wella, personal communication, February 10, 2022, lines 247-252)

*Oo kay you are creating a scene kag hibian ka. Amo gd na isa ko ka difficulty. Andaman mo lang sa balay. "[ Ok, so he will create a scene and bawl his eyes out. That is the most difficult thing. I will get you when we get home.]* (Susie, personal communication, February 1, 2022, lines 141-142)

*" So it was really a struggle samun before nga indi aware ang Mga tao kung mag palak si Yohanne, so medjo ano siya. Amo gid naya na notice ko" [ So it was really a struggle with us before that we were unaware of the traits, and Yohan would resist. I noticed this is who he really is]* (Susie, personal communication, February 1, 2022, lines 87-88).

*" Like amo gid na sya Ang pinaka kwan pinaka greatest challenge mo gid, dal-un mo siya sa mall, mag wild siya Eh indi na siya baby, right? May edad na siya, and then ma wild lang siya gulpi indi mo Siya ma... ang discrimination nga Makita mo sa chura sang mga tao is grabe." [ Like this is who he really is. The greatest challenge was to bring him out to the mall, and he would have a meltdown, and he was not a baby anymore, right? He was already of age and still had a meltdown unexpectedly. You can see so much discrimination from people's faces around]* (Alora, personal communication, March 31, 2022, lines 223-226)

### **Maximum Patience and Tolerance are Exerted**

It goes without saying that being a parent to a child with autism, one needs to have patience beyond words. If you look at all the struggles of these parents and what they do for their children, one can attest that patience is their strongest virtue. With the complex features of autism, parents surely need to have overflowing patience every day. Even first-time, overwhelmed, clueless parents, they learn to acquire this trait in their rich experience raising this child. It develops even more with time. In many setbacks, parents have extended their patience beyond their limits. Even in one autism blog by Seattle's Children's Hospital, Research, Foundation, a mom of 2 children with autism was interviewed. When asked what

her special tool and advice was in raising them successfully, she claimed it must be "patience" (The Autism Blog, 2016).

Parents in this study mentioned the importance of having patience and how it has helped them become bigger people in difficult situations. You cannot raise a child with autism without it. Some were baffled by how they have gone through the years raising their child, knowing they either do not have the patience or are short of it. The effects of raising a child with autism to parents are like the disorder itself, complex and multifaceted. Apart from doing the usual parental obligations, parents need to have or develop some more patience than they have. It is needed all the time when dealing with the child. Their unique behavior can test the parent's patience beyond their tolerance threshold. It does not just pertain to dealing with the behavior but to other aspects, such as seeing progress in their development, going through different programs and seeing which one works best for school performance, disciplining them at home and in public, etc.

*" : I can... Well, honestly ang negative is that me as a person, indi ko pasensyosa. So amo na Gani kis-a ga ano ko nga jusko ngaa gina hatag mo mani sakon ya man nga wala ko pasensya Daw amo na bala. Ako pa bala nga jusko ka kwan gid, kaluoy lang na sang bata kung kwan... Daw amo na bala, so that's the negative thing kay te wala ka patience for... kung kis-a bala Gina test ka gid, so wala ka pasensya... te daw ga kwan ka nga anhon koni man, ngaa ako pa [I can...well honestly the negative part is me as a person, I am not patient. That is why you question sometimes my God why was this given to me and I am not patient, it was like that. My God I am really, I just pity the child. So the negative side is I don't have the patience for this...Sometimes I am also being tested and I really don't have patience. ..So I ask what do I do with this now, why me](Alora, personal communication, February 2, 2022,lines 138-142)*

*" But the bottom line...the bottom line is, ang patience mo, dapat sobra sa lawas mo kay kung wala ka pasensya. Grabe you can... maubos guid tuod imo pasensya. (ma go beyond threshold mo?) kay i'widen mo guid ya perspective mo nga, amo na sila. Kay te lain na sila mag'react, dapat extra extra guid siya." [But the bottom line is, your patience should be overflowing. You will run out of it sometimes, and it gets worse. You have to widen your perspective about them, and yes, they are different, and they are really like that. They reach differently, and they are really extra.] (Helen, personal communication February. 23, 2022, lines 500-507)*

*" And of course the patience and you accept things as they are." "It is different from hands-on parents. The patience gid ya is enormous compared sa gina bayran mo mu. Lain guid ya ang pasensya, gaka-urot gani pasensya sang ginikanan, ano pa ayhan ang iban nga tawo?"[ The patience is really enormous compared to what you are paying for. The patience is really different. If parents run out of patience, how much more other people] (Helen, personal communication, February 23, 2022, lines 266-268)*

*" : Siguro ano gid eh, ina bala ang patience, you have to be patient and then as much Para indi sya ma upset but in cases nga indi gid pwedi, then you Will just have to bear his irritability." [I think you have to be really patient as much as you can so that they will not get upset, but in cases it is not applicable, then you will just have to bear his irritability] (Susie, personal communication, March 21, 2022, lines 16-18)*

*" Hambal sg Jack n Jill Teacher "Mam ang patience bala namon asta di, ang imo ya ato na nag lapaw na sa atop." Because gina-try guid ya ang imo nga patience kag ang imo nga pag'widen sang imo nga perspective bala nga. indi ka dapat ma'akig tudo kay ti amo na sila ya mu. Tapos pasensya gid, try to let them understand" [A Jack n Jill teacher said, " Mam, our patience for this can only go so far, but yours goes beyond the roof, overflowing. Because he really tests your patience, you have to widen your perspective,*

and you do not have to get very mad because they are what they are. And you really have to be patient, try to let them understand](Helen, personal communication, April 4, lines 221-225)

" Yes. I have become more patient. Grabe, ang pasensya mo daw natilawan guid to the extreme level guid ya. Tapos ang perspective mo in life, daw nag'change na"[ Yes. I have become more patient. The patience you had is at an extreme level. Then your perspective in life has really changed] Helen, personal communication, April 4. 2022, lines 456-457)

" do I even have the Right patience para sa amo ni? Lord indi koni kaya kay wala ko pasensya. Amo na permi ano Mo eh, if enough, daw ka wala ko Lord pasensya so indi ko kabalo kung kayanon koni siya. But then there are times Makita ko nga ang iban mag react kay Yohanne, Makita mo nga, "Ay may pasensya ko gali? [Do I really have the right patience for this? Lord, I cant do this anymore I have no more patience left. That is always your concern, if you still have enough, it is like Lord I don't have patience anymore and I don't know if I can still go on. But then there are times I see how Yohanne reacts and then I realize " Oh I do have patience for this".] Alora, personal communication, March 31, 2022, lines 412-419)

## **Facing Different Types of Social Stigmas**

### **Autism Social Stigmas Faced by Parents**

Parents of autism are very susceptible to different types of social injustices, so much so that out of these sad encounters, they may have built a wall, avoided situations where there are lots of people, received unsolicited advice, picked up a fight, turned a deaf ear to others and may have developed anxieties. Families of children with ASD have faced insurmountable humiliation, exclusion, and parental stigmatization. All participants in this study had their share of discrimination and attack from people they do not know and people closest to them. No parent can escape the injustice given to them by society. Discrimination against the family of children with ASD happens wherever they are and whoever is in their company. Sometimes they learn that the best way to deal with society is just looking the other way and building themselves up, so they will not fall apart when stigmatized. Sometimes they try to explain, but when it is done repeatedly, sometimes to the same crowd, they know educating them will still not help, people will never fully understand, and they are back from the beginning.

" I really have to ano... parang, I mean for me, you have to treat him like a normal person like he is, you know parang... there are times bal-an nga for some parents, gina Kwan gid ya bala nila... they are treating it nga daw ka special gid, grabe gid ang ila nga kwan I mean for me I think it would help kung eh treat ta man... Eh treat ko man sya as like a normal kid. " I really have to...like treat him like a normal person. There are times when other parents, you know, treat him like he is a special child. I mean, for me, it would help if they treat him like a regular child.] (Alora, personal communication, February 4, 2022, lines 43-47)

" Nga amo na... nag amo na imo bata amo amo na. Tapos there are friends pa kung kisa Mahambal, "Ay blessed koya kay akon mga bata normal" te syempre ikaw ya, ay sorry ha Amo na hatag ni Lord" [ Your child became like that . There are also friends who sometimes give comments like "I am more blessed because my child is normal". So if you hear these, Im sorry but this is what the Lord has given me.] (Alora, personal communication , February 4, 2022, lines 343-345)

so Nang other people who don't understand gina judge ka because you don't – paminsaron nila is indi ka kabalo mag disiplina bata mo. Indi ka kasaway" [ So for those who do not understand, they judge you because you do not...they think you do not

know how to discipline your child. You cannot reprimand him.] (Alora, personal communication, March 31, 2022, lines 213-217)

“ *Indi man ko namian nga ara da siya tuod, alam-alam sa iya, pero ang panulukan ka iban nga nanay, daw monster siya ya? So kalaw-ay diba?* [ I didn’t want him there anymore to be honest, he is very smart but other parents look at him like he is some sort of a monster. It doesn’t look good right?] (Wella, personal communication, March 29, 2022, lines 264-267)

“ *ti ang ako ya nagalalain na ko ya eh kay nagasaka ko di sa stage sa academic excellence pero palaaway bata ko. Which is sa akon ya indi siya ya palaaway, na’bully na naman siya.*” [ I feel so bad because I go up the stage during academic excellence awarding but my son is a trouble maker. But for me, he is not a trouble maker, he is just bullied.] (Wella, personal communication, March 29, 2022, lines 297-299)

“ *Ina ang mga things nga wala na experience sang iban nga parents ya. Dayun may ara man iban nga, “Ay, kasalawayon.” Mga amo na bala nga comment* [ These are the things other parents do not experience. Then there are others who say, " oh, he is disruptive". Those kinds of comments.] (Helen, personal communication, April 6, 2022, lines 174-179, 181)

“ *Regular parents. Diba always taman na sila maka’salamuha, diba? Tapos matikal sila ya nga, “Ah ang bata ko amo ni, amo ni.” Te, ah makadlaw na lang ko ni ya. “Ah te, okay. Mayo eh.”* [ Regular parents. We always encounter them right? Then they will show off about their children and say “ my child is like this like that”. So I just laugh it off. Well then ok. Good for you.](Helen, personal communication, April 6, 2022, lines 184-186)

*Amo guid na. Bullying guid bi, kay amo na ang gakatabo sa iya. Te high functioning siya? Ti naga’compete-compete siya. Sa Sidera man kami before. Gin endorse siya sa regular and kung sa regular ka ala pakialam ang Sidera d bala?”* It is like that. It is bullying. That is what happens to him. He is high functioning, right? He usually joins competitions. We were in Sidera (SPED school) before. He was endorsed in regular class and if you are in regular class teachers do not care about you. ] (Wella, personal communication, March 29, 2022, lines 231-234)

### **Parental Avoidance of Social Situations**

A combination of several social stigmas parents of individuals with autism encounters every so often makes it very challenging for them to enjoy life with their child in public like normal people. There are several reasons why they choose to stay away from gatherings or places where there are people. For one, they already fear getting negative judgments from both people who may not understand why their child behaves the way they do. Another reason is that they just want to avoid situations that may evoke their child to have another meltdown in public. Next, they would know if their child will not be able to handle certain situations.

Lastly, they know bringing their child along might cause them and people in the area stress. In any case, they start behaving inappropriately. This is a sad reality for parents because they cannot have the quality of life they wish for themselves and their children. In the case of some parents in this study, admittedly, they too had moments wherein they chose either not to be in social situations or decided not to bring their child to some social gatherings.

“ *Lain ya kung open ka kung anong disabilities sang bata mo. Nang... mabuligan ka sang iban nga tawo. Kung ano man da, may ara man di bi nga gaano sila nga, “Ay amo na ang bata mo.” So what? So what kay amo na siya ea?”* [ It is different when you are open about

your child's disabilities. Other people can help you more. There are others who also say "Oh that is your child?" So what? So what if he is like this? ] (Wella, personal communication, March 29, 2022, lines 228-230)

*" wala ko pakiaalam sa mga neighbors ko kun mag akig man gid kodi sa ila ma Hambal na sila kagahod sa amon balay. [I do not care about the neighbors whenever I get mad at my kids. They say our house is very noisy.] (Alora, personal communication, March 31, 2022, lines 231-234)*

*" Usually kay te accepted man sya, and then although we choose lang affairs that we can bring him into especially if it's just a pure family affair we would bring him because they could give allowance pero kung (but if its) it's a big party so wala siya gina dala (we don't bring him)" (Susie, personal communication, March 21, 2022, lines 59-62)*

*" Ti amo tu, ginpauntat ko na lang siya dayun sa regular. Tapos amo tu, nag'Happy Beginners na lang kami. Pahimuyong na lang guid ko ya sa SPED Program. Indi na ko magregular, which is tanan bala nga gahambal sa akon nga kanugon, kanugon. Pero siling ko ya, wala ko ya nanugunan. Oo, siling ko 3law ala ko ya nanugunan kay mas manugunan ko ya kung mag bayolente siya." [So I made him stop attending the regular class. Then we transferred to Happy Beginners. We will just stay with the SPED program. I wont consider regular to which is much opposed by others they say it's a pity we will let go of that chance. But I tell them I don't feel it's a waste. Yes its not a waste because it will be worse if he becomes more violent ( from the regular class)] (Wella, personal communication, March 29, 2022, lines 308-312)*

### ***Lack of Understanding from People and Getting Blamed***

It sometimes gets even worse when people give remarks trying to blame them with a baseless point of view that distorts their way of thinking, and they end up going through some memories questioning themselves if they were to blame for everything their child is now. A lack of understanding about autism by people can lead them to judge, discriminate, stigmatize, and blame parents for their child's condition. People can conclude and fault the parents because they do not know enough about the spectrum's complex traits.

Aside from dealing with all the problems attached to raising this child, it is beyond hurtful and very unfair to parents when fingers point at them whenever there are complications about their child, may it be physical, behavioral, or whatever aspect, and this can play with the head of these parents. They may start doubting themselves and wonder if anything is amiss about their actions that made their child turn out the way they did. Parents sometimes must educate others about what is happening to their child during incidents where their child attracts people's attention. No matter how much they explain, many people will never really come close to understanding it. During the interviews, participants in this study recalled many occasions where they felt like they had to explain to others what was going on with their child but sensed that they did not come close to still understanding it. This becomes an exhausting cycle for parents on how they deal with society.

*" Kung parents ka nga may( if you are a parent with ) special kids ka, you have to be very patient and open minded. That you can never explain everything to anyone and they would never understand you." ( Helen, personal communication, February 23, 2022, lines 241-243)*

*"I have friends ga amo na nga ang mindset ya nga she is more ano... Yohanne!... She's more blessed because normal ang iya mga bata, kadlaw ka nalang eh tulokay nalang Kamo sang mga friends mo, ay okay ndi ko gali palangga ni Lord? Daw amo na bala, and There are people gidya nga indi maka inchindi"* [I have friends with that mindset, and she is more what...Yohanne!...She is more blessed because her child is normal, I just laughed it off, and my other friends and I just looked at each other, oh ok the Lord does not love me? It was like that, and some people could not understand the situation.] (Alora, personal communication, February 4, 2022, lines 347-350)

*" So nag Grade 1 siya, ga'compete guid tu siya ya galing kay second grading, indi na guid maagwantahan ang iya nga behavior. Nahyper na siya plus nagapang-away na siya which is pang-away niya tu is para mag-depensa sang kaugalingon niya tungod gina'bully siya sang mga classmates"* [ So when he was in grade 1, he would compete but during second grade, his behavior was getting out of hand. He was very hyper, and he was aggressive, but this was only because he was defending himself from his classmates who were bullying him] (Wella, personal communication, March 29, 2022, lines 243-247)

*" Siling kay ti, amo man... ang bata amo guid na ya kay ang bata, may special needs. Ti siling ko "Huo, amo na gani, ti ang ara nga parent, indi na siya ya kainchindi."* [ They say that is it...the child is like that because he has special needs. So I also said, "Yes, that is exactly why he is like that. That parent really could not understand] (Wella, personal communication, March 29, 2022, lines 336-338)

*" So far, diri sa aton, pero ambot may ara guid na pero kay may parent guid ya nga katig-a."* [ So far here with us, but I do not know if there are really parents that are too close-minded/ hard.] (Alora, personal communication, March 31, 2022, lines 351-352)

*Kung mag comment sila bala, they do not understand what is really going on. Te indi mo man na siila ya mahambalan, ma'discussionan mo sila sang tanan-tanan nga gaka tabo sa kabataan mo. Kay tungod they will never understand"* [When they comment, they do not understand what is happening. You cannot also educate them or have a discussion with all of them about everything going on about your child. It is because they will still not understand] (Helen, personal communication, April 6, 2022, lines 174-179/ 181)

*" Yes. They do not understand that "Uy. There is amo na." Indi na sila ya aware because they have never been in your situation eh."* [ "Yes. They do not understand that. Hey. There is this, and there is that. They are not aware because they have never been in your situation.] (Helen, personal communication, April 6, 2022, lines 188-189)

*Pero amo na eh, indi ka nalang maminsar kung ano Ang eh hambal sa imo sang tao, kay I heard a lot of tao nga gina basol ko kay na pa imnan ko Bulong si Yohanne, you know naman how people are diba?"* But that is the way it is, just do not think about it, the one that people may say because I have heard a lot of people blaming me for what happened to him like I must have drunk something while having Yohanne. You know how people are, right?](Alora, personal communication, February 4, 2022, lines 338-341)

*" Oo, maminsar gid na sila ya nga gin kwan mo imo bata, siling ko indi ko gani ka inchindi Ngaa nag amo na si Yohanne guro... may ara kana... may mga times man nga sa tuod-tuod Lang I thought sala ko, gin ano kona sa man, basi wala ko gin take care akon nga Kaugalingon sang nag busong ko, naka inom ko bulong, waay ko kabalo amo na bala..."* [ Yes, they will really think you did something to your child that's why he is like that. I said I could not even understand why Yohanne became like this...you have...there were moments when I honestly blamed myself. I thought it was my fault. I

did something. Maybe I did not take care of myself during pregnancy, I drank something, but I do not know.] (Alora, personal communication, February 4, 2022, lines 353-356)

*" Actually gina blame ko man akon nga kaugalingon siling ko basi bala kay tungod wala ko siya Gin pa therapy nag amo na sya, nag budlay nagid. Amo lang na akon nga kwan kay te Financially we cannot afford it years before ang indi nakon kaya"*[ Actually, I blame myself; I said maybe because I did not enroll him in therapies that's why he got worse. That was my concern because, well, financially, we could not afford it years before, and it was impossible for me.] (Alora, personal communication, February 4, 2022, lines 405-407)

### ***Having Incessant Worries and Concerns About the Future***

Parents of children with autism constantly think about their children, and worrying about them becomes a daily habit. There are many reasons why they are constantly in fear of something for their child. Some of the littlest things and some worries are there to stay throughout their lifetime. When one's child is more unique, and the condition is more complex such as being under the spectrum, the concerns are so different from those of regular parents to their neurotypical children. Even if they know there will be some family members who can help them, they see their child develop and improve, there are therapies and programs available for their child, and lastly, laws that protect children with disabilities, parents repetitively have thoughts that make them fear for their child.

As much as they can, they try to be around and oversee their child's every move, and they cannot bear the thought of leaving their child behind in the future. All participants in this study had some degree of constant worries for their child, some moderate and some severe. The most common worries noted are about the child's future if people will take care of them once their parents pass, constantly praying for their child and entrusting them to the Lord, and lastly, they worry about their employment and whether they can cope.

Parents know that they have no control over the future no matter how they overthink and worry, so aside from having future anxieties constantly, they also turn to something which they know can help ease this, and that is constantly praying for their child. Participants in this study during their interviews have also shared their everyday prayers for their child, begging the Lord and entrusting things to Him. Praying for their child is as constant as worrying for them. With their faith, they firmly believe that this event in their family is still the work of God and He has a purpose. Even though they may occasionally struggle to see God's reason for this and ask why it has happened to their child, specifically those they love, they believe they are being heard. Prayers can somehow appease their situation.

According to Pastor John, a founder of Desiring God, he sometimes meets parents of children with disabilities and discusses with them what they go through as parents and their questions for Him. He explains it is sorrowful for them, especially if they get the opposite of what they have hoped and prayed for, but he also says, "It is not wrong to rejoice in the gift of a healthy child, but it is wrong not to rejoice in the gift of a child with a disability (Piper, 2018). They face confusion and discouragement as they face their struggles, yet they still bring these doubts to the Lord. A lot of sorrowful parents turn to God and continue to pray because, despite so many questions, prayers can give them a sense of tranquility and reassurance. Current medical findings and research until now cannot come up with a definite explanation for the cause of autism and a cure for it. Hence, parents turn to their spiritual beliefs to help them understand their purpose and ask for guidance. God's word (Gannon, 2019).

*“ My greatest worry is what will happen in the future. Nga, “Ay what will happen? Will they survive nga wala ko?” Amo na greatest worry ko. “ [ My greatest worry is what will happen in the future? Like “ Oh what will happen? Will they survive without me?” That is my greatest worry.](Helen, personal communication, February 23, 2022, lines 169-170)*

*“ What I fear for them is crossing the street because I want them to experience by themselves kay they are adult na eh. Galing way nadayon kay na COVID. So na stop to. [What I fear for them is crossing the street because I want them to experience it by themselves because they are already adults. But we could not push through because there was COVID, so it stopped.] (Helen, personal communication, February 23, 2022, lines 154-163)*

*“ Ang struggle lang guid ya is amo na... naano ko lang guide a nga sa ulihi.... sa ulihi, paano siya maka work? Pano sila bala magaan sang government accommodation. Amo guid na bala ang ano sa aton, ang struggle sang single parent kay mastand by lang guid sila ya.[ My struggle is...like that...I just need to guide them that in the end...in then end how will he be able to work? How will the government provide accommodation. That is just my opinion, the struggle as a single parent because they might just be an idler/ jobless.] (Wella, personal communication, March 29, 2022, lines 192-195)*

*Huo basi indi ya makaya ang stress sang employment dapat mabuhì siya, nang... either ma business na lang siya or ano.” [Yes, he might not cope with the stress when employed, but he has to survive...either he can do business instead or something else.](Jessie, personal communication, April 1, 2022, lines 305-306)*

*“ Huo, tuod tuod gid na ya. Ka'ano sa akon eh, ina bala ang... ang mind ko bala wala gapahuway. What if... what if, what if bala. So may Plan A, Plan B naman na dapat. Kay kung indi mag'ano ang plans, liwat naman ah.” [Yes that is really true. I am, you know...my mind doesn't rest. What if...what if you know. So there is Plan A, There should also be Plan B. Because if the plan doesn't work out, we start all over again.] (Helen, personal communication, April 6, 2022, lines 484-486)*

*“ we have to prepare for his future kay ti ara man dyapon ang acceptance, basi indi siya ka... Base indi ya makaya ang stress sang ano bala Miss sa employment” [We have to prepare for his future because there is still acceptance that he cannot.. he might not be able to cope with the stress as an employee] (Jessie, personal communication, April 1, 2022, lines 299-300)*

*Pero I pray gd ya Cel, to be very honest ang prayer ko gd ya is “Lord unahon niya Lang ya kwa sa akon si Jepoy” everyday of my life. I pray for that nga later bala, lain gd ang Siblings ang mother mag sacrifice ya.” [But I pray Cel, my prayer is “ Lord, please take Jepoy first” everyday of my life. I pray for that for later. Mother's sacrifice is different from their siblings.] (Susie, personal communication, Feb. 1, 2022, lines 187-192)*

*“ Yes and I pray for that everyday ya nga Lord unaha lang tan isa akon si Jepoy. E outlive ko Lang tani si Jepoy. Always gd na ya ara sa prayers ko. Nga kami tanan ma outlive siya namon.” [ Yes, and I pray for that everyday that the Lord will take Jepoy first. Hopefully, I can outlive Jepoy. It is always in my prayers that all of us can outlive him.] (Susie, personal communication, February 1, 2022, lines 194-197)*

*“ So many nights that I have prayed for that. Everytime I prayed for that, I really cried mo, nga, "Lord, I am not asking anything anymore. Just provide me with my kids. That is enough for me. I do not ask anything for myself. And Lord, in the future, which I cannot control, Ikaw na bahala sa ila. Amo na lang guid na. Kay I cannot solve anything kay ti in future wala nata mu, which is indi na ya naton ma let go.” [ Lord, in the future, which h I cannot control, you take charge of everything. That is the only thing because I cannot solve*

anything in the future because I am no longer around, and this is something we ( parents) cannot let go of] (Helen, personal communication, February 23, 2022, lines 189-193)

*“ Amo lang na, I cried and I pray, nag pray guid ko ya kay Lord. “Lord I know nga kami tanan mapatay. And... and okay guid ko da ya. Gina ‘accept ko guid na ya Lord, I accept your plan. Pero ga’ayo lang ko Lord nga indi lang subong.” Amo na hambal ko sa Iya, “Indi lang subong siling ko kay ang kabataan ko gagmay pa.” Amo lang na napangayo ko.” [ That’s all, I cried and prayed, I really prayed to the lord. “Lord I know that all of us will die sometime. I am ok with that. I really accept that, I accept your plan. But I ask you one thing, don’t let it be now. That’s what I said. I said not now because my kids are still young. That’s all I ask for.] (Helen, personal communication, February 23, 2022, lines 352-355)*

*“ always in mind is nga, you pray to God nga Unahon lng sya kwa. Noh? That he will go ahead of me.” [ It is always in my mind that when you pray to God, He will take you first. Right? That he will go ahead of me.] (Susie, personal communication, February 1, 2022, lines 18-19)*

*“ Tapos ang ano pa guid kay ti subong, teenager na siya, makadto guid na siya sa adulthood ang problema sa aton, ti wala accommodation for employment.” [ Then right now, he is already a teenager and eventually will reach adulthood. The problem with us here is that we do not have accommodation for them for employment.] (Wella, personal communication, March 29, 2022, lines 167-169)*

*“ Oo, kag ang struggles guid ya eh. Ti paano siya bi maka ‘work sa ulihi eh. Kag, not all people man bala indi make understand sang ila nga behavior. “ [ Yes and the struggles most especially. So how will he be able to work later on? And not all people can understand their behavior.] (Wella, personal communication, March 29, 2022, lines 167-169)*

*“ oo makagraudate ni siya sa college, sin-o mabaton sa iya sa work? Amo na” [ Yes he can graduate from college but who will hire him for work later? That’s it.] (Wella, personal communication, March 29, 2022, lines 317-318)*

*“We have to prepare for his future kay ti ara man dyapon ang acceptance, basi indi siya ka... Base indi ya makaya ang stress sang ano bala Miss sa employment” [ We must prepare for his future because acceptance is still a factor. He might not be able to cope with the stress from being employed Miss.] (Jessie, personal communication, April 1, 2022, lines 299-300)*

*I think that is the common worries man with parents with special kids. Amo guid na. Even when I talk to other parents, that is their main concern. What will happen if we are gone? Will they be able to support themselves like that?” [ I think that is the common worry of parents of kids with special needs. That is it. That is their main concern even when I talk to other parents.] (Helen, personal communication, February 23, 2022, lines 170-173)*

*Kay amo guid na ang greatest fear sang parents, ang amo na... what if madula ko, if madula ko, wala na guid sila ea, kay ti wala na nga daan si papa nila. Ma’solo na guid sila ya” [ Because that is parents' greatest fear, it is that. What if I will not be around? If I go, then they will not make it because you know their father is no longer around. They will be on their own.] (Wella, personal communication, March 29, 2022, lines 122-126)*

*“Si manang ya ang maano, pero ti syempre, ti si maanang sa ulihi, magka ‘pamilya siya, amo na, si mabilin guid sa iya. So kung duwa sila, ti dapat may ara pa guid nga mabilin pa guid sa ila. [ His older sister will take over, but of course, she will have her own family eventually and he will be left behind. So if its just the two of them, there should be someone*

else who will still be there for them.] (Wella, personal communication , March 29, 2022, lines 126-130)

### ***Facing Inevitable Financial Strains***

The families of individuals with autism are impacted more by financial struggles than other families. This theme explores the hardships of parents about their family income and trying to make ends meet. Parents must set aside extra expenditures for their child's treatments, which can deplete the family's budget. However, they have no choice but to continue with them because their child's development might regress without it. Many people do not realize the cost of raising a child with autism, which leaves a severe financial strain on the parents, who sometimes ponder if they will still have enough left for the remaining days.

Parents admit being unable to afford the treatments and blame themselves for any signs of regressed development observed when they miss treatments. She acknowledges that the child needs therapy, and it will entirely be her fault if her son does not receive it continuously. Similarly, participant 4 admits that therapies are costly and tries to still have her son receive them even if they cannot afford them. She turns a blind eye to the financial constraints because she knows her son needs it, and they cannot afford even more for him to skip them.

Likewise, they talk about their worries that come doubly because aside from struggling to pay for therapies, taking the child around in centers while being a working mother is also very stressful. Moreover, raising a child with autism can be very high maintenance because of their preference for their essentials, such as food which can be costly. Individuals with autism have food selectivity because they are usually hypersensitive to textures, smells, and tastes, so it is common for them to be very choosy with food.

*“ Ang struggles mo bala financially tapos amo na ang... syempre ga ano kapa na kay syempre Imagina bala nga... nga ano mani man, ngaa... ngaa... ngaa ka... nga indi sya...[ Your financial struggles and it's the...of course you have to...Imagine, why did this happen to me...why? Why not her?] (Alora, personal communication, February 4, lines 169, 175)*

*“ Actually gina blame ko man akon nga kaugalingon siling ko basi bala kay tungod wala ko siya Gin pa therapy nag amo na sya, nag budlay nagid. Amo lang na akon nga kwan kay te Financially we cannot afford it years before ang indi nakon kaya ” [I blame myself because maybe I did not let him have therapies, so he got worse. That was my point because financially, we could not afford it years before, and it was beyond my capacity.] (Alora, personal communication, February 4, 2022, lines 405-407)*

*“ kabudlay bala sang amon nga travel. So kung kis-a kung maglaw-ay tyempo, indi kami katabok, plus financial problem. Te syempre, financial grabe guid ya, dira guid ka ya permi ya ma'anuhan mu.[ Travelling was difficult for us. So aside from financial problems, it was also hard for us to cross and get to the centers if the weather was bad. The financial struggle was really the worse. It hit us the most.] Wella, personal communication, February 10, 2022, lines 132-134 )*

*“ but gina pa music therapy niya kag gina pa occupational therapy niya, so Whatever my tita does to his son, I try to do it as well kay Ji. But depende lang sa resources Man bala namun makaya ” [But she makes him go to music therapy and occupational therapy, so whatever my aunt does to his son, I try to do it as well to Ji. But it depends on our resources if we can still afford it or not.](Jessie, personal communication, February 16, 2022, lines 139-141)*

*“ nag pa’consult kami to kay Doctor Alejano dayun nagpa speech therapy kami tu sa Jack n Jill. Mahal mahal guid ya miss ya, ga ubo guid kami sang balayran pero gina-agwanta lang na namon” [ We had our consultation with Doctor Alejano and went to speech therapy in Jack n Jill school. It was a really, really expensive miss, and the fees were making us cough out everything we had, but we endured everything. ] (Jessie, personal communication, April 1, 2022, lines 93-95)*

*“ other thing pa guid sa mga bata, they are very choosy sa food. Kung sa sister ko pa, “Grabe ka high maintenance sang mga kabataan.” Daw ka amo na bala haw. Hahah.” [Other thing also about my children, they are so choosy when it comes to food. My sister said “ Your kids are so high maintenance” It was like that. Hahaha.] (Helen, personal communication , April 6, 2022, lines 193-195)*

### ***Entrusting the Child to Others is a Problem***

It goes without saying that underdeveloped social skills are the biggest problem for individuals with autism. The trait of all types of autism makes it hard for them and others to communicate, interact or read them as a person. If parents sometimes struggle to talk to them or get them to correspond to their verbal and non-verbal cues, other people will have a hard time many times over. It is not easy for parents to leave their child with ASD to relatives or other caretakers for reasons such as the child cannot respond to them when told, does not understand the child's odd behaviors, they do not make eye contact, seem withdrawn and act uninterested to other people. Parents are not completely at peace when someone else looks after their child while they are away. This theme discusses the dilemma the participants experienced when they left their child to either relatives or caregivers and the experience did not turn out pleasantly. The participants faced a similar crisis in deciding to leave their child with someone else. Some participants had to make decisions and major changes in their routines when no one else could look after the child.

Parents claim hired caregivers do not stay long and give up on the child after some time, and they have to start over again after the entrusted nanny leaves. They had to think of ways to return to their routine or find another way to adjust to their new situation. Participants 1, 2, 3, and 5 had an unpleasant experience when they had to leave their children because they had to work for the family, but others did not know how to handle their children at all; hence their child's behavior worsened over time. They noticed the obvious disintegrating attitude, which concerned them because it erased the therapies that helped them, and what they had worked hard for would go to waste. The change feels like a developmental crisis for them.

Participant 1 knows this well and worries about the people her son will be with in the future because she knows no one can equal her when raising him. Reluctantly, participants 3, 4, and 5 do not have peace of mind when leaving their child with someone else, even with a trusted relative, because something bad might happen to the child while they are away. They know how unpredictable and complicated the child is when they throw a fit and understand that others do not know techniques for how to handle difficult behaviors. Participant 4 wants to teach her son independence, and she does so by allowing him to join school activities and trusting that teachers watch him and know how to handle him. All the time, she admits she cannot get the thought of worrying about her son and wondering how he is doing. Participant 4 wants to teach her son independence, and she does so by allowing him to join school activities and trusting that teachers watch him and know how to handle him. All the time, she admits she cannot get the thought of worrying about her son and wondering how he is doing.

*“ akon man lang concern sa ulihi ya eh na even if he has two siblings, what will happen to him later? Ga worry gd ko ya. Pero hindi naman na distress ka gd kay te ultimately ma hambal ka hindi ta man ma balan Bwas ah [ My concern in the end even if he has 2 siblings is what will happen to him later on? I really worry about that. But you will not be so distressed because, ultimately, we also do not know what will happen tomorrow]. (Susie, personal communication, February 1, 2022, lines 187-192)*

*“ Pero I had to give it up. Kay ari d indi siya kaya ni nanay. So nag puli eh. [ But I had to give it up. Because if he is here, my mom cannot handle him. So I had to go back home.] (Alora, personal communication, February 4, 2022, line 167)*

*And then wala ko help sa manila for them, so pag puli kodi after I think three months? I think that was after three months or six months, nakita ko nga ang iya bala... wala Na sya naga sunod, waay na sya naga follow sa amon. Since ng Kadto kotu, asta subong wala nani sya naga pati sa amon kung isipan ko sa, kay te amo na. Sya sang una sa amon kung isipan ko sa, ma stop nasa subong wala nana sya naga amo na. nakita ko pag puli ko ngaa nag amo na sya, so ang gin himo ko nag puli. [ And I could not get help in Manila for them so I went back home here after I think 3 months? I think that was after 3 or 6 months, I saw that his...he could not obey, he did not follow us anymore. Since I left and went there, until now he still does not obey our countdown because of what happened. Before, when we count out loud, he stops his behavior but now he doesn't do it anymore. When I came home, I saw he has changed so what I did was come home for good. ] (Alora, personal communication, February 4, 2022, lines 152-165)*

*“ kabudlay kun' i'bilin mo sa balay nga indi... indi bala kabalo mag'deal. Sang una, hadlok ni sila sa iya mu, kung ibilin, nahadlok na sila” [ Its hard to leave him at home because no...they don't know how to deal with him. Before, people here were scared of him. If I leave him, they are scared.](Wella, personal communication, February 16, 2022, lines 191-192)*

*I did not go to work and then had a <sup>second</sup> child, si Stephen. Then amo na na (Then it was like that), I really have to stay with them. But eventually, went to work na (already). Nakita ko different ang development sang bata kung ibilin ko lang sa timbang, sa yaya.( I saw how different their development is if I entrust them to the helper or the nanny” (Helen, personal communication, February 23, 2022, lines 258-266)*

*“ kis-a kung indi mo pag-ibilin sa cellphones, indi man sila mag'paymuyong. Ti let's say nga ara ko sa balay ma'control ko but then kung sa timbang na, indi na nila mahimo. Amo na sa ang pinaka'difficult ko gid.” [ Sometimes, if you don't leave a cellphone to them, they will not also stay put. But lets say I am just home so I can control them but if I leave them to our helper, they don't know how to do it. This was the most difficult part.] (Helen, personal communication, February 23, 2022, lines 323, 325)*

*“ Ang gin himo ko, sala ko man kay gin padala ko nadi ang mga bata kay nanay kay Wala may mabantay tu sa amun mo kay hambal nila, medjo indi siya bala na manage ni Nanay sang maayo, te patay natu si nanay medjo indi ko mana siya ma ano, gin himo ya Man tu guro ang pinaka the best nga mahimo ya kay Yohanne, pero daw nag lala nagid si Yohanne sang gin dala kona di sa. [ So what I did, it was also my fault, I sent them back to my mom because there was no one to look after them here and I was told that she could not manage the kids well. My mom already died so its like I could not tell her what to do. Im sure she also did her best whatever she can do with Yohanne but Yohanne really gotten worse when I sent him here.] (Alora, personal communication, February 4, 2022, lines 443-447)*

*“ wala na si teacher, mabilin na lang ang parents, ti tapos siya ang Yaya niya bi. Ti ang Yaya niya, indi man bi kabalo maghandle, ti nang ano guid siya ya eh. “ [ If the*

teacher is gone, the parents are left with them and he is with his nanny. So the nanny also didn't know how to handle him, so that resulted in what he is.] (Wella, personal communication, February 10, lines 255-256)

“ *Kag kadako guid sang difference after few months sang ako na nag bantay sang mga bata. Kay lain guid ang deperensiya.*” There was a big difference after a few months of me taking care of my kids. There was a really a big difference.] (Helen, personal communication, April 6, 2022, lines 530-531)

“ *ang may greatest fear ka –kay amo na nga kung madula ko or... or.. syempre kung kis-a ginaano mo... ginapamisar mo guid nga base nabilin siya sa balay, base magkui tu sa sang kuryente, makuryente tu sa or what if abi may sunog or may earthquake, pano siya makasurvive? Kay ti kung indi mo na sa daan piliton maggwa, indi guid na sa ya magwa ya*” [ My greatest fear is when I go ahead or... or...of course sometimes I do...I think about what they are up to if I leave them at home, he might be tinkering on something like electric wired and might get electrocuted or what if there is fire or there is an earthquake, how will he survive? Because if you don't force him to go out he will not also go out. ] (Wella, personal communication, March 29, 2022, lines 159-164)

*Kaluoy sang bata, stressed pa ko kung ara ko sa work kay base nang-away naman tu siya, base nangagat naman tu siya, so wala peace of mind. Mas mayo na lang tu nga wala na lang.*” [pity the child, I am stressed when I am at work because I keep thinking someone might be bullying him again or maybe he bit someone again so I don't have a peace of mind. It is better if he is away from them.] (Wella, personal communication, March 29, 2022, lines 264-267)

“ *May worries ka guid ya kay ti ato siya sa layo nga lugar, ang safety ya. Ti pero umm galing kay salig man ko bala sa teacher haw, sa Boy Scout nga teacher. Dapat bi, salig lang man kay para madevelop man ang bata.*” [ You have worried because he is far away, and you think about his safety. But then, umm, I just really have to trust the boy scout teacher. You really have to have trust so your child will develop.] (Jessie, personal communication, April 1, 2022, lines 197-199)

“ *Kag ang future naman lang ang gina-concern ko ya all the time. “What will happen to them without me?” Daw ka amo lang guid na siya.*” [ My concern all the time is the future. What will happen to them without me? It seems like that] (Helen, personal communication, April 6, 2022, lines 87-88)

*So, but of course, if they are alone, if they are by themselves, we can never control the environment.*” (Helen, personal communication, February 23, 2022, lines 216-219)

“ *I am actually free kay nag day-off ang amon nga helper so I have to stay home. Even mabilin ko na sila but I am still scared dyapon nga basi bala magkala 'sunog kung mag luto-luto sang kung ano haw*” [ I am actually free because it is our helper's day off so I have to stay home. Even if I leave them home, I am still scared that maybe they will set the house on fire if they cook or something like that.] Helen, personal communication April 6, 2022, lines 437-439)

“ *Wala, amo guid na ang indi magtagal ang yaya. Imbis nga yaya, ga'gwa guid na ya tanan ya. Ga'gwa guid na ya tanan nga bida kung may yaya ya.*” [ No, that's the reason why the nanny wont stay long. When it's the nanny taking over, their behaviors come out. It all comes out when they have a nanny] (Wella, personal communication, February 10, 2022, lines 183-184)

“ *Hyper gid ni sila ya. Grabe grabe guid especially ang eldest ko. So ang matabo malayas ang timbang, may ubra ko. T bulos2 kami sang husband ko eh. As in ang sleep*

*ko bi for example mag sulod ko sa kwarto ara mana ang durwa ka bata. “ [They are hyper. They are extremely, especially my eldest. So what happens is my helper will walk out on us while I am at work. So my husband and I will take turns. If I sleep, the two kids will be with me inside the room.] (Helen, personal communication, February 23, 2022, lines 283- 285)*

### ***Theme 3: Seeing the Silver Lining in Being Parents to a Child with Autism***

Many studies on the lived experiences of parenting children with autism and the results in these studies expose the negative side of it. This unique theme has emerged, and it focuses on the good side of this study. Parents have seen many types of silver linings in raising children with autism. During their interviews, all participants also felt the joys and fulfillment of parenting a challenging child and raising them has been rewarding one way or the other. This theme focuses on parents seeing the silver lining in being a parent to a child with autism, and two sub-themes have come up during the data gathering. The first sub-theme is parents seeing their efforts in raising their child paying off through the child's successful development, which becomes a teaching moment for them. The second sub-theme is parents receiving genuine and pure love from their children. The third sub-theme is parents becoming resilient and braver in life's trials. The last sub-theme is that parents feel blessed in other aspects of their lives.

#### ***Seeing Parenting Efforts Paying Off***

This sub-theme emerged after the parents shared all their persistence and endless effort exerted in being hands-on in raising their child with autism. Seeing their child's red flags turning into milestones is one of the biggest reliefs parents of children under the spectrum can experience. It is solid evidence that all their dedication to raising their child the best way they know how and witnessing some skills improve and develop before their eyes make them realize all their work did not go in vain. This is also clear evidence that parents are crucial and much needed in the success of the development of their child with autism. Aside from giving themselves a pat on the back for doing a good job, receiving affirmations from others who see their child improve makes them even prouder.

*kay even my husband na meet niya ang mga bata. Na shock siya ya. . lain gd ya ang mga bata no? nag amo na sa, siling ko “of course! Gina pulawan bugtawan ta na. and ang effort ta na. so far kahit papaano, nag normal bala ang ila pangabuhi” [ Even my husband met my kids. He was shocked. The kids are different now. That’s what he said. “ Of course! I stay up late and wake up early and exert all effort I have and so far their lives have normalized.] (Helen, personal communication, February 23, 2022, lines 310-312)*

*“ So ang positive side guid na, amo na siya tapos amo na, biskan nano ko ka strict sa iya... ka'firm. So nakita ko man ang ano bala... nakita ko man ang result kag miski nagka'gasto kami sang una sa iya nga therapy, intervention... ang tanan nga struggles, pero ano siya, nakita ko na kung ano siya subong nga ma'manage siya ya kag independent katama, mabilin ko lang siya ya.” [ So the positive side is, he is like that, I have been very strict with him...firm. I have somehow seen the...even if we have spent so much on his therapy and intervention, I can see the result...all my struggles, and I have seen now how he can manage himself well and he is independent, I can already leave him.] (Wella, February 10, 2022, lines 145-149)*

*“ Ah wala, wala na siya mga amo sina ga bite. Sang gamay lang guid tu siya. Nadula siya pagsugod niya therapy. Pagsugod niya therapy, two weeks lang nakita ko guid ang ano... ang improvement.” [ Oh no, he doesn't bite anymore. That was a long time ago when he was still young. It disappeared once he started therapy. 2 weeks into his therapy, I saw his improvement.] (Wella, personal communication, February 10, 2022, lines 163-167)*

*“I don’t know if you can consider him as an autistic, maybe at the beginning he was but with the early intervention and siguro sa support of his family and siguro ang iya pagid nga gin himo ko nga intervention sa iya is music therapy because early paman sya Nakong g nano” [ ...and maybe the support of his family and all the interventions and one is music therapy because I had him do therapies early.] (Jessie, personal communication, February 16, 2022, lines 135-137)*

*“Tapos amo na, daw mga happy ka man biskan sa mga simple nga mga achievements bala. Kay siya ea, ginakwa ni sa mag compete bala sa mga vocal solo. Tapos nang... tanan nga mga event, nang... kabalo siya bala, siya ang nagahost, sa mga simple things lang na nga na’achieve niya, mahappy ka na bala. Ginatudluan ka sang maka’ appreciate sg simple things. “ [ After that, you feel happy even over the simple achievements. He is chosen to compete in vocal solos. Also...in all events...he knows how to host, those are just simple things that he can achieve, it really makes me happy you know. This teaches you to appreciate little things.] (Wella, personal communication, Feb. 10, 2022, lines 151-156)*

*“My sense of fulfillment. told my cousin who was here before nga “Hala kalain na guid ka kabataan. Ang amo na siya. Daw ka indi na sila mahambalan nga special guid nga mga bata. Daw may self-control na sila.” Te of course it’s coming from somebody eh. Kabudlay na bi kis-a kay parehos sa aton, parehos sakon kay ako lang di sa balay, makit-an ko lang ang difference but then again, lain guid kung iban nga tawo bala ma’notice. Even some parents nakamuno na sang-una sa akon nga, Day, lain guid bala ang kabataan.” Siling ko, “Ngaa nang haw?”... “Sang una sang gamay-gamay, naga’liligid na di. Subong hu, ka mga nagmi na gid.” My sense of fulfillment. My cousin who was here before said “ Oh the kids are so different already.” Things like those. They cant be considered special kids anymore. It seems like they have self control already. Well its coming from someone else already. Its different if someone says it. Its difficult to tell like for us, because if its just me here in the house, I also see the difference but if its other people who notice the improvement its even better. There were even some parents who told me before that my kids are really different already. I asked how and they said before they used to roll around the floor and have meltdowns but now they are so behaved.” (Helen, personal communication, April 6, 2022, lines 328-337)*

### ***Parents Experience Genuine Love***

Although social skills and affection are challenging and usually not generally evident among individuals with ASD, these children can love back people, especially their parents, in unconventional ways. They may seem distant and non-demonstrative with their emotions, as any typical individual with autism does, but participants in this study have proudly narrated their relationship with their children. Behind all the trials in raising their child, they have all shared the genuine and unfiltered love their child has for them, which has made up for the stress and exhaustion that came with raising an individual with autism. Here, participant 1 has explained the joys of feeling sincere love from her son, which makes her day every time. As unique as autism goes, participant 5 talks about the unique love beyond measurable and incomparable to the love other regular kids show their parents.

Love is in its purest form, even if they are not verbal but just candidly shows it without a filter. Similarly, participant 4 recalls how her son shows his love with appreciation by acknowledging the efforts she has made for him. Other children do not often do this at such a young age, but this participant was surprised by the unique way the child made his love and concern felt in the most subtle yet straightforward way. Any parent would have been emotional with his words. The participants expressed their gratitude and felt very lucky to be given a child

who genuinely loves them and showers them with different ways of sweet affection. This makes them realize their children make them happy and feel grateful to have them in their lives.

*“ So siguro ang silver lining sina is nga amo na eh na you having a child with Handicap, ka budlay gd ya. Pero at least it brings fulfillment gd ya sa imo. Then amo na eh Ka mga loving na sa ila. They are so loving and so innocent and so trusting. Ka refreshing gid sg love nila. “[ So I think the silver lining there is having a child with a handicap is really difficult. But at least it brings fulfillment to you. Then also they are very loving. They are so loving and so innocent and so trusting. Their love feels so refreshing.] (Susie, personal communication, February 1, 2022, lines 156-159)*

*“ ang namian ko lang ya galling sa ila is to appreciate bala ang love, indi ma measure eh. Di mo ma measure ang... Ang affection sang bata bala. Nga lain guid sila sa iban nga bata because they show affection, emotions, nang hambal ko gina, wala guid filter. Nang nag ligad bala, I have COVID, and then, I never told them nga I have kwan... so isolated myself diri sa separate ko nga room. And then the eldest, nanuktok siya. Ti hambal ko siya, “Never come in never go too close sa door ni mama.” May pertahan, may lamisa na di lapit sa door. Siling ko, “Why didn't you stay upstairs? Didto na lang ka stay... “You know I will stay here because I know there is something wrong with you that you are not telling me. I will stay here to ensure that I am here if you need something.” And he is knocking on my glass window, “Are you okay? Are you okay?” [ What I really like about them is appreciating their love. You cannot measure it. You cannot measure the affection of the child you know. They are different from other children because they show affection and emotions, which you can say have no filter. Last time, I had COVID, but I never told them about it...so I isolated myself in a separate room here. And then the eldest came knocking. So I told him, “Never come in, never go too close to mama's door.” There was a table near the door. I told him, “ Why didn't you stay upstairs? Just stay there. You know I will stay here because I know there is something wrong with you that you are not telling me. I will stay here to ensure that I am here if you need something.” And he is knocking on my glass window, “Are you okay? Are you okay?”] (Helen, personal communication, February 23, 2022, lines 325-336)*

*“ Even JI accepted that and told me that, nakibot man ko gani pag hambal ya nya mama if You went to ano kuno America I would not have been this way, and it would have been very difficult for me, amo na hambal ya” [ Even JI accepted that and told that, I was surprised myself when he said "mama if you went to America to work, it would have been very difficult for me. That is what he said.] (Jessie, personal communication, February 16, 2022, lines 186-188)*

*“They are so sweet, and they're loving if they don't feel good about some things they will say that to you. Daw wala ya bi filter2 nga mahuya ka pa ya or ano or whatsoever at least you know right away. “ [ It seems like they have no filter and are not embarrassed or whatsoever at least you know right away]( Helen, personal communication, February 23, 2022, lines 41-43)*

*There are times Ga kwan man ko sa iya nga lipay-lipay gid ko, palangga-palangga mo gid siya kay te syempre He's very sweet diba? Kis-a ga hambal man ko, hay salamat Lord kay nang amo na bala, feeling ko blessed gd ko ya with him”, [ There are times that I am very very happy with him, I love him very very much because he is so sweet right? Sometimes I also say thank you Lord because of that, I feel so blessed with him.] (Alora, personal communication, March 31, 2022, lines 497-500)*

*“ang unconditional love guide ya eh. Amo na ang positive gd ya” [the unconditional love above all. That is the positive side of it.] (Wella, personal communication, March 29, 2022, lines 156-157)*

### ***Parents Develop Resilience and Become Braver in Life's Trials***

What does not break you will only make you stronger. A quote is the closest one that can explain this sub-theme very plainly. In a world where very often individuals with autism are misunderstood and stigmatized, parents of these children have found ways to get by and hence have also improved their problem-solving skills. Over the years, experiencing this almost daily has made parents of children with ASD resilient in life's trials, and they admit to becoming braver in difficult circumstances. This sub-theme tells how the mindset of their parents made them more courageous during their storms, and giving up was never an option for them. They had to keep going for their child because in being parents to children with ASD, sometimes there is no plan B. They cannot be defeated by their weakness nor by the negativities of society against them and their child. Wallowing in difficult situations gets them nowhere, and they do not have the luxury to cry it out for so long is not in their watch. Unlike other parents, they do not have time to grieve, so they pick themselves up and do what is right for their children.

They go through difficult situations and endure until it gets done. Even a participant had suicidal thoughts, but she snapped back to reality instantly and reminded herself that her children depended on her. Calling it quits was never a possibility, and she knows she cannot rely on others to solve it but herself alone because she is the caregiver of the child, period. Traumatic events may weaken them to the core, but they become braver and train themselves to be emotionally and mentally stronger as a parent. Participants in this study know they cannot waste time grieving.

*“ Grabe, as in. Pero eventually na overcome ko man ah. May mga time na ko ya gani nga may mga suicidal mode na ko ya sang una, tuod-tudo guid na. But because of them, naga’ano pa guid ya ang doubts mo ya sa likod sang ulo mo. “Ay day, may bata ka pa ya naano ka tungod sa lalaki?” Amo na... sila daw... daw... they keep you moving. Way ka choice, you have to move kay maano na lang sila?” [It was to the extreme. But eventually, I was able to overcome it. There were even times I was in suicidal mode before, in all honesty. But because of them, you still have some doubts left at the back of your mind. "hey, you still have kids waiting, and you are going to lose it over some guy? It was like that... they were like...like...they keep you moving. You do not have a choice. You have to move on because what will happen to them?] (Helen, personal communication, February 23, 2022, lines 550-556)*

*“ I think ang gina-remind ko lang guid ya, I have to be emotionally stable and ina.. ang inang... ang gina’remind ko guid sa self ko, "My kids are different from others. I cannot expect them to do the same thing," I think what I keep being reminded really is I have to be emotionally stable, and that...that...is what I keep reminding myself.] (Alora, personal communication, March 31, 2022, lines 80-82)*

*“ Daw grabe bala ang... daw mahambal mo bala nga bisan ano pa kabudlay sang kabuhi, I have to be strong, I cannot lose kay ngaa? Ga’depend sila sa imo eh, indi puwede maperdi kay ara sila. Kay if I fail, they would fail” [Its like too much...you can say that no matter how hard life is, I have to be strong, I cannot lose, why? They depend on you of course, you cannot be defeated because they are there. Because if I fail, they would fail.] (Helen, personal communication, April 6, 2022, lines 460-462)*

*“ Ina balang wala ka na ya time to grieve. Amo na, kay ti amo na kinanglan mo i’face guid ya reality nga amo na. Kag te, ma’stand ka on your own nga amo na sya. Tapos, ti kinanglan mo siya e therapy and itabok tabok. “ [You know you have no time to grieve. That is because you need to face the reality of it. And you need to stand on your own. Also, you need to have him in therapies and cross ( family lives in Guimaras island, and they*

need to cross the sea to get to the city where the clinics are)] (Wella, personal communication, March 29, 2022, lines 126-129)

*"They have the luxury of crying out loud and doing things they want para lang ma relieve sila. As for me, I do not have that pleasure because I cannot do that. Indi ko na puwede mapakita sa mga bata ko nga I'm weak because they will go weak. Indi ko puwede kapakita sa mga bata ko nga gahibi ko, but they knew that, ah nga naghibi ko but will never show them that I cry, indi guid ko. Kay because gina'adapt ka nila kung ano ka... if you are weak or strong. Indi puwede nga weak ko."* [They have the luxury of crying out loud and doing things they want to relieve themselves. As for me, I do not have that pleasure because I cannot do that. I cannot show my child I am weak because they will also be weak. I cannot show my kids I cry, but they know that I cry, but I will never show them that I cry. I would never. Because they will adapt to who you are if you are weak or strong. I cannot be weak.] (Helen, personal communication, February 23, 2022, lines 568-573)

*"So gin'face ko guid ya ang ano ya... ang life nga amo na eh. Nga kinanglan maging maisog ko kay ti syempre five years old pa lang siya daw peak guid na ya sang hyperactivity ya ya kag tanan nga tantrums."* [So I really had to face it... this kind of life. I really needed to be brave because since he was five years old, it was the peak of his hyperactivity and all his tantrums.] (Helen, personal communication, March 29, 2022, lines 120-122)

*"Kay ara sila ga'fight eh. If I surrender damo-damo guid apektado. Amo lang guid na permi, sila ang drive ko, sila ang strength ko. Sakon nga amo na... sige nalang kaya na biskan ano pa ka budlay, kaya pa. Daw amo na"* [Because they are also fighting. If I surrender a lot will be affected. This is what I always have in mind, they give me drive, they are my strength. For me... it's ok even no matter how difficult it may get, I can still go on. It's somehow like that.] (Helen, personal communication, March 29, 2022, lines 363-365)

*Indi ko puwede ka surrender"* [I am not allowed to surrender.] (Helen, personal communication, March 29, 2022, lines 361)

*First thing, how do we manage the time? Especially if you are working or have a business, leaving your kids sa ila mga yaya, amo guid na. Kay te, me as a single mom, indi puwde nga indi ko mag ubra kay I have to work for them eh. I have to pay the bills. I have to pay for their tuition. So amo na ang difficulty ang mag pa'raise guid bala sa kabataan haw"* [If you have a business, you have to leave your kids to the nanny. Because I am a single mom, I cannot afford not to work because I have to earn for them. So that is the difficult part of raising the kids.] (Helen, personal communication, March 29, 2022, lines 317-322)

*Yeah, because you have to be strong eh. Biskan weak ka na inside, but then you had to be strong. Kay they are very sensitive ang kids eh. They... they, kung ano ka bi nga parent, amo man na bata mo eh. Kung weak ka, weak man na bata mo, so you have to show them that biskan budlay, kaya ah."* [Even if you are weak inside, you still have to be strong. They are very sensitive kids. Whatever the parent is, the kids will be the same. If you are weak, the children will also be weak, so you must show them that even if life gets very difficult, you can still do it.] (Helen, personal communication, April 6, 2022, lines 563-566)

*"In case lang... in case lang guid kung ano guid man matabo sakon, promise lang guid ya sakon nga indi mo pag'pabayae ang akon kabataan amo lang naya."* Siling ya, "Nano kaya imo ya man nga amo na?!" I am so weak na guid ya Miss mo. Pero amo lang eh. Fighting spirit lang ya gapon. Sila man gapon ang reason behind the back of my mind. *"Indi ko puwede mitumba kay sila ara pa."* [If something happens to me, please promise me you will not leave the kids. That is all I ask for. She said, "what is wrong with you?!" I

am so weak already, Miss. But that is really it. I still need to have a fighting spirit. They are still the reason behind my mind and why I do things. I am not allowed to fall because they are still around.](Helen, personal communication, March 29, 2022, lines 347-351)

*“ When you look back, tingala ka man bala pano ka naka survive, pero naka survive ka gid kay Ano bala, daw may gabulig man bala dyapun sa imo bala haw”*[ When you look back, you also wonder how you were able to survive, how did I survive because it seems like there is still something or someone still helping you.] ( Alora, personal communication February 4, 2022, lines 232-233)

### **Receiving Blessings in Many Forms**

Being blessed to be a parent to a child with autism is not something one would hear so often. These parents want what other regular parents go through with their children during their development, but one would say autism can change that. Aside from seeing the silver lining to being parents to these children, parents have admitted to realizing they have been blessed more than others in another aspect of their lives. When a door closes, a window opens is somehow their quote for this sub-theme.

Participant 2 generously shares her story wherein she felt like the whole world collapsed before her eyes as she was just starting to embrace the fact that she is a mother of a child with autism. For this, she had to give up her dream job, and other sad events took place one after the other. She did not think her misery would end, but as soon as she picked herself up and started anew, blessings just came her way very easily. She realized she attracted more luck in life than others, which is confirmed by her friends too. Similarly, participant 5 also realized that after going through some stages of grief before accepting the reality of her children and deciding to be a hands-on mother to them, she admitted to realizing her blessings.

*“I stayed home and eventually had a business. Dira man ko nag prosper. Did you regret doing that??No I did not regret it, I even regret nga nag work ko “ [ I stayed home and eventually had a business. This is where I prospered. Did you regret doing that???! No, I did not regret it. I even regret I worked before.]* (Helen, personal communication, February 23, 2022, lines 270-272)

*I make decisions gina pangamuyu-an ko mana then I realized kay Naka kwa man ko ubra bala nga work from home and right now Doing better than sang ara ko sa google”* [I make decisions which I really pray for then I realized I was able to get a job which makes me work from home and right now, I am doing better than I was working with google.] (Alora, personal communication, February 4, 2022, lines 169-175)

*“ So feeling ko all these things nga gina hatag sa akon feel –sa tuod-tuod lang I feel blessed kay kahapos sakon, wala ko gaka wad –bisan gamay akon sweldo at first then gin hire, then promote manager then director level. I don’t know how I do it pero wala ko gaka wad-an, may mga friends ko na 100k a month sweldo but indi kaigo sap ag bulig sa family nila. “ [So I feel like all these things (trials) given to me, in all honesty, I feel blessed and everything becomes easy for me, I do not run out of anything even if I had a smaller salary from the time I was first hired then I got promoted to a manager level then a director level. I do not know how I did it, but I did not run out of resources. I have friends who even earn up to P100k a month, but it is not enough to help their family.]* (Alora, personal communication March 31, 2022, lines 339-345)

*“ there are times gali nga nang, daw sa iya bala, daw ka blessed ka Man bala usually kay te there are a lot of opportunities ang akon nga mga friends they’re Thinking nga daw gapalapit lang bala sakon ang mga gracia or mga... daw ginapalapitan ka Thinking nga daw gapalapit lang bala sakon ang mga gracia or mga... daw ginapalapitan ka Bala sang abi nila ha, nang pareho na daw mga ubra koya ya nga daw ka gulpiyada lang bala Nga*

*daw pareho na, may opportunity somewhere, may work nga ma offer, may ma send Sakon nga eh invite ko for the job so there are times nga daw kahapos nang, daw kahapos Sang life mo ah.*” [ There are times also like with him, I am blessed because usually there are a lot of opportunities and my friends think that blessings just easily come to me. It is like I attract them for instance I can instantly have a job, it is like there is an opportunity somewhere and work is offered. Someone will send me an invite for that job and it just comes easily, my life is easy.] (Alora, personal communication, Feb. 4, 2022, lines 239-245)

*“ Gaan ka man sang daw blessing that would help you ano sang things sa mga balay mo kay te Akon mga friends mga dalaga na sila mo mga wala bata, and then there was this ano nga Daw recent lang kay te nag storyahanay sila, kay te mga breadwinner man, storyahanay sila Dai noh, te amo ni, amo ni, wala ta mayo bilin nga kwarta, kay nang pang bayad sa balay Amo ni, amo ni, daw mga reklamo bala, hambalan ko sila eh, siling ko mga dalaga kamo bala Gin amo kona sila, siling ko ano haw kung nabudlayan kamo how much more ako nga eh single parent ko. Galalain sila kay indi sila kaigo, siling ko Nag paminsar ko siling ko, dalaga sila gani indi sila kaigo may mga bulig pana sila sa mga Utod nila nang kwan sa mga parents nila tapos indi sila kaigo. Pero ako ya at the end of the Day, wala ko gaka short. Daw ka amo nabala. So kung paminsaron mo bala miss daw kahapos. Daw kahapos, wala ka gaka wad-an, kaluy-an bala wala ka gaka wad-an kumbaga bala may help ka, each and eveytime, ang hambal bala nila nga daw gina buligan ka gd. “ [ You will be given blessings that will help you with things for your house. You see my friends are single and have no kids and recently they were talking because they are also breadwinners, they were discussing how they do not have much money left because they have bills to pay for the house. This is what they usually complain about and I told them you guys are still single. I did that. I said if you are having difficulties making ends meet how much more with me, a single parent. They were distraught because their money is not enough. I was thinking they are single and have other siblings to help them out with their parents and still it is not enough. But with me, at the end of the day, I never fall short. It seems like that. So if you really think about it miss, things seem easy. Life is easier, I don’t run out and it seems like I always have help each and every time. They say it seems like help is always given to me. ] (Alora, personal communication, February 4, 2022, lines 282-286)*

*“ Amo nab ala kisa dumdumon mo mas better nalang ni. May ara ko Friend ya na bata addict. Mas mayo nalng guro may autism sg sa addict. Kung kis-a cognitive restructuring man lang eh. Ina bala, you look at the glass half full or Half empty eh. Pareho sina Mabasa mo lang sa news or you heard from the radio or even sa News na mga addict ang bata patyon ang mama. Te? Si Jep ya ka loving gd na sa iya. Wala Gd na ya evil sa iya ah. Actually, on his own ok siya.” [ You know, sometimes I remember that this is better. I have a friend whose child is an addict. It is better to have a child with autism than an addict. Sometimes it is just cognitive restructuring. It is like you are looking at the glass half full or half empty. Similar to the news you read or hear on the radio or that addicts kill their moms. So? Jep is very loving. There is nothing evil in him. Actually, on his own, he is ok.] (Susie, personal communication, February 1, 2022, lines 181-187)*

### ***Forgoing Personal Career Goals and Gaining Valuable Life Lessons***

This theme emerged since all the participants in this study were career driven, and all had a promising future, yet they made the same decision. Their plans changed when they knew they had to raise a child with autism. Despite being qualified for their dream jobs with earnings that provide a comfortable life, parental instincts still prevail, and it does not take long for them to decide which one will be prioritized. The burden of stress among parents who have autism, or any disability for that matter, is high because it comes with much-added responsibilities

outside the usual child-rearing responsibilities of regular parents. Finances are often a big source of stress because parents have extra expenses for their child with autism, yet they still sacrifice their careers to attend to the child's needs, leading to lesser income for the family. Parents adjust their work and work demands according to the child's needs, and often, they just must let go of a good position in the office or even forego future career growth if they can sense it will compromise their child's development.

Participants in this study shared their experiences, all emotional, on choosing to dedicate their time to their child over their career development. They later learn the effects of a neglected and under-supervised child with autism. They would rather invest in their successful development than their career advancements. No number of paid therapies and programs can equate to their presence and being hands-on with their child's growth, so leaving them in the hands of other professionals is not an option. They choose to see their child gain independence and life skills they would need for their future than their success.

*“there are a lot of opportunities actually um, sang... this ano Lang sang... I think two years ago nag work ko sa google Philippines bala sa manila, so I got That opportunity nga maka work sa very nami-nami gid nga job, I really love the job nami-nami gid sang work, name-nami sang kwan but I really cannot relocate them both Kay te si Yohanne, subong palang ni sya nag daw kumbaga bala they need a lot of getting Used to sa is aka environment, indi mo sya pwedi ma kwan kwan lang sya ka agad-agad. [There are a lot of opportunities actually during...just this...I think that was two years ago when I was working at Google Philippines. I got that opportunity to work, and it was a very nice job. I loved the job, and the work was really good, but I cannot relocate them both because, with Yohanne, they need a lot of getting used to a new environment. You cannot just abruptly change his routine so suddenly] (Alora, personal communication, February 4, 2022, lines 152-165)*

*, I had to leave that job Nagpuli gid ko, nag resign gid ko from google which is I think um is an opportunity of a lifetime. A dream job. “ [I had to leave that job, I went home, I resigned from Google, which I think was an opportunity of a lifetime. A dream job.] (Alora, personal communication, February 4, 2022, lines 152-165)*

*“ Oo, that’s why, amo na ginapangita ko guid ya nga work nga masudlan ko nga work... ga’pili guid ko ya work. Ina balang , mahambal ang iban nga, “Kanugon sa imo, nurse ka, dapat nag-ubra ka sa amo ni (abroad), amo na, amo na, kay dako ang sweldo,” no, wala ko ya ga’after sang dako nga sweldo. Ga’after ko ya nga ang workplace ko, madala ko ang bata ko. So amo na, nga madala ko sila nga makita ko... makita ko siya bala nga ara.” [Oh that’s why, I was really looking for a job that I could do...I would choose my work. Other told me, its such a pity and waste, you are a nurse, you should have been working abroad, this and that, your salary would have been very big. No I am not after a big salary. I am after a workplace where I can bring around my child. I can bring them and see them always.] (Wella, personal communication Feb. 10, 2022, lines 186-190)*

*“ So sa amo palang na I think I did the right decision because ano miss mo may, choice ko Bala nga eh pursue ko ang abroad kay te nurse ko mo, nag skwela ko nursing to go abroad Ky tungod akon nga mga siblings nurse na sila tanan abroad na sila tanan ako nurse man ko Pero ari lang kodi because of JI, I cannot leave JI alone so amo na nang... [So with that, I think I made the right decision because, miss, I had a choice to pursue my career abroad. I studied nursing to go abroad because my siblings are also nurses, all working abroad. But I am here because of JI. I cannot leave JI alone.] (Jessie, personal communication, February 16, 2022, lines 190-193)*

*“ ang diri sa aton, ang ano, ah... sa reality, ang sa employment, amo guid na ang sa aton. Kay te, once may special sa needs ang bata mo ya, daw wala guid ya chance nga*

*maka...maka 'work"* [The reality here with us is...the reality of employment is really like that for us. Because once you have a child with special needs, you will not have a chance to really work as much.] (Wella, personal communication, February 10, 2022, lines 113-115)

*" Actually, mam, I gave up my career for my future just to stay with my kids. I was actually hired abroad eh when I graduated, but I got pregnant with the eldest. And eventually, I realized that there was a problem.* (Helen, personal communication, February 23, 2022, lines 256-258)

*" no. I even regret nga nag ( that) work ko (I).* (Helen, personal communication, February 23, 2022, line 273)

*" I had to give up ang amo na nga ubra, pag puli Kodi ang amo na nag agent nalang ko eh may position before ano nako manager nako... amo na sya ang mga negative things Nga kinanglan eh accept mo kung may amo kani kay"*[ I have to give up that kind of work, when I went back home here, I just became an agent but before I had a managerial position. Those are the negative things that need to be accepted if you have something like this.] (Alora, personal communication, February 4, 2022, line 185-186)

*daw indi, daw Kumbaga bala ara nana gin hatag nana sa imo tapos eh give up mopa dyapun tungod sa iya Pero at the end of the day kay sini hu kay te I had to give it up, gina pangamuyo ako everytime I make decisions gina pangamuyu-an ko mana then I realized kay Naka kwa man ko ubra bala nga work from home and right now Doing better than sang ara ko sa google"*[ no, it looks like the opportunity was already given to you but then you have to give it up because of him. But at the end of the day, I had to give it up. I just pray for it every time I make a decision. I prayed for it, then realized and saw the good side of my job: I can work from home right now. I am doing better than when I was working at Google.] (Alora, personal communication, February 4, 2022, lines 169-175)

*" sonag decide ko to leave my job and it was really –uh kumbaga dream job kona siya, name-nami Gid na akon nga ubra, te daw ara kana bala sa management level and all, and then Bayaan ko siya and then nag balik kodi sa Bacolod nag balik ko as agent. As in nag start gd ko ya from scratch"*[ So I decided I had to leave my job, and it was really a dream job, it was the best job ever, and I was almost at the management level then I had to leave it and go back here in the province Bacolod to start again just an agent. As in, I had to start from scratch.] (Alora, personal communication, March 31, 2022, lines 315-319)

*" Umm. Sang una ma work ko tani gwa man. Pero wala ko na gin'dayon. Kay te syempre, researcher man to tani sa Australia. May friend ko nga may ma'go-out. then she said nga qualified daw ako, ma'go kami. So siling ko, indi pa puwede kay may bata pa ko."*[ Before, I was also planning to work outside too. But it did not push through. Of course, I was supposed to be a researcher in Australia. I had a friend who went out. Then she said I was qualified, then we could go. So I said I cannot because I still have a child] (Helen, personal communication, April 6, 2022, lines 497-500)

*Dream job gd. pero gin'give-up ko to. Wa'ay ko gintapos ang training kay nagpuli naman ko. Indi na lang ah kay indi ko ma'sacrifice ang kabataan. Kabudlay daan mag'minasakit ang kabataan bisan ga'ubra ka, ang imo nga bu-ot bala ari di. So indi puwede ma'amo sina,"* [It was really a dream job but I gave it up. I did not finish my training because I had to go back home again. Nevermind because I really cannot sacrifice my children. Its difficult if the kids will get sick and you are working because your mind will be here. So it cant be like that.] (Helen, personal communication, April 6, 2022, lines 524-527)

*“Akon lang ya (in my opinion) is because I felt that J needs more guidance that’s why I sacrificed my career For him, maybe that’s a downside for other people but for a mother, you are really looking Forward that your son will eventually stand up on his own and that what I am aiming for so aimed for him to be a regular student now I am aiming for him to be self-sustaining adult in the future.” (Jessie, personal communication, February 16, 2022, lines 175-179)*

## **Eidetic Insight**

### ***Transformed by Parenting Experience: Perspectives, Challenges, and Optimism of Parents of Children with Autism Spectrum Disorder in Their Adulthood***

Parenting a child with autism is very challenging is an understatement, and what most people know about them is just the tip of the iceberg. If they are given more venues to speak about their lives as parents to individuals with autism, they will generously do so. Many of their experiences and thoughts about it are still unexplored and unknown to many people, and they continue their battle until their child reaches adulthood. In this study, nine common themes with sub-themes emerged from the participants' experiences. Namely, these common experiences are dealing with extremely challenging behaviors of their child at home and in public, receiving social stigmas, having constant worries for the child about anything and everything, having the need to teach the child life skills and independence every chance they get, making career sacrifices for the child, finding a silver lining in the midst of all the struggles, experiencing inevitable financial strains and having a hard time entrusting the child to someone else because it causes problems both to the caregiver and the child himself.

Generally, parents go through numerous difficult experiences while raising a child with autism. As unique as the characteristic of autism goes, aside from the known hardships they encounter almost daily, some unique and new struggles would come out now and then. Parents know what it entails to raise their child under the spectrum, even if accepting their circumstances as a parent was not easy from the start. They may have seen red flags from the beginning and somehow have a hunch that there are some concerns to clarify about their child's development. Although there may be a tendency for some to delay it and make excuses for the signs, parental instincts would kick in, and they seek an explanation.

For all parents with a child like this, receiving the news of the initial diagnosis from doctors will never be easy, and they often go through the different stages of grief before they come to terms with fully accepting this reality. Varying emotions are experienced, all not happy, the moment the news is handed to them. They shed tears, feel heartbreak, and have false hopes thinking they can still remedy this, and for some, it can lead to rifts in relationships between spouses or relatives. They cry for both reasons, for themselves and their child. They know they will have to go through many challenges and difficulties in life as soon as they face the world and carry this new responsibility, even if the road ahead may seem dark from their starting line. They also cry for their child because he/ she will go through as many struggles as they would when they all want them to grow like other neurotypical children and experience normalcy in life.

While always doing what is best and thinking about the child's welfare, parents have received tremendous uncalled-for remarks, judgments, put-downs, and all other social stigmas from the community. Some relationships may be tested to the fullest and may cause a major rift in the end. Others may also give up on trying to help them because of a lack of understanding about the child's condition, leaving the obvious that parents are the main caregivers and only they truly know how to handle their children. Despite all these, parental

instincts will always prevail, and mothers, most especially, will see no other option for them to carry on raising and being with their child.

Their unique experiences in raising a child with autism are tough, but it has undoubtedly made them resilient in life's trials outside of their struggles with their child. It has taught them to snap out of their misery quickly during such events and realize they do not have the luxury of wallowing for a long time like other parents because they have a child depending on them on a different level. Their mindset often tells them that quitting is not an option. After many lessons from their experience, they also find silver linings in having a child with autism. Nothing makes them happier than seeing their child develop and progress, and they take pride in knowing their efforts and sacrifices are paying off.

Overall, raising a child with autism comes with so many struggles and trials far different from the experiences of other regular parents. No matter how uncertain things are for parents from the beginning of this journey, they will face and bear all the stress, the social stigma, the sacrifice of self-goals, difficult behaviors that will test them beyond their threshold, and financial worries because there is no plan B. They will cry when they remember what they have been through but also get emotional when they talk about their unconditional love for the child. They will admit to prioritizing their child over everything else, even if it may burn some bridges later. This unique experience leads to resiliency and unmeasurable courage that will make them go on and be the best parents they can be no matter what others say about it or whatever new trials life can give them.

## **Discussion**

### **Theme 1: Insights on Parenting of Children with Autism in their Adolescence**

All the participants in this study shared their journey from learning about their child's condition upon seeing red flags until finally being given the news about the diagnosis. Initially, parents become in denial and think they can remedy the child's situation eventually to cope with the painful news. It is no question that news will rock the parents, but some of their spouses took it worse than them. After being devastated, only one of them had to force herself to come out of the trance and thought of many ways to go through it and what help she could get. In a study by McCabe and McCabe (2013), he says when parents learn their child has special needs, the joy of having that child leaves its place and is replaced with negative emotions such as shock, anger, denial, and regret, and parents become intensely concerned.

A study in China with 78 parent participants with kids with autism stated that these parents initially felt shocked and in denial. They went through a mourning process, and it was an experience like having lost a child, especially for the mothers than the fathers (Girli, 2018). Denial occurs because it is profoundly terrifying to accept a child's handicap. After all, it comes from a deep-rooted fear that their child will struggle and be rejected by society (Logsdon, 2022). Like any mother receiving the news and trying to accept it, and in this familiar line spoken by parents, it is obvious that they realize they cannot change the situation or make it go away. It is beyond their ability to solve it, and the only choice is staring at them, which is accepting things outside their control.

Having the mindset of accepting the child is an important key in unlocking what needs to be done for their child because, without it, the parent cannot fully think all the time logically for their child. They know this. In an article under *Frontiers of Psychology*, a study videotaped and evaluated the interactions between parents and their children. It revealed that those more accepting of their child developed more attunement with each other. The findings highlighted the importance of parents' ability to accept the successful implementation of plans and

understand and improve their relationship as a parent and child (Di Renzo et al., 2020). Also, according to an article by a behavior analyst, for parents who are just starting their autism journey on the right foot means acknowledging first the challenges, grief, and other emotions before bravely heading down the road (Zahiry, 2022).

Three participants had a series of bouts with their spouses when the other one took it badly, and they became different people, ultimately leading to separation for the 2 participants. Mothers focus on the child rather than prolong dealing with their spouse's differences. Case in point, in some studies on fathers' involvement in raising children with ASD, it is found that they have poor attendance in IEP meetings, conferences, and small representations in support groups compared to mothers. Mothers are also more involved in therapies and other programs for the child (Naseef, 2015). The acceptance came late for some spouses. Their spouse's lack of emotional support and cooperation leads to resentment and marital fights. A study on parents' perspectives about their child with ASD reveals that mothers are often the primary parent participants in research about autism; hence there was a difference in the self-reported stress and coping mechanisms between mothers and fathers (Grebe et al., 2022).

Another probable reason for this phenomenon of fathers having a late reaction to the reality of their family life is that, according to research, men are less likely than women to admit to uncomfortable or negative feelings. Hearing something as devastating about their offspring as these conflict with their masculine gender role (Addis & Mahalik, 2003). All participants in this study expressed their varying worries and concerns for their child, a daily occurrence. Any parent always wants the best future for their child, and during their growing years, aside from sacrifices, they make various plans to ensure their child is secured later.

In the case of parents of children with autism, they have constant worries about the future and what will happen to their child, especially if they will not be around, and have various worries about the unknown yet. It persistently bothers them even if they see the child doing well and gets assurances from others, they can entrust them with. In one study, 51 parent-participants over 50 who did one-on-one interviews discussed future-related concerns about their child becoming adults. The study emerged with four themes from the parent interview, and they were all related to parents' fear of the future, which is very similar to the participants' responses in this study (Marsack-Topolewski & Graves, 2020). Worrying thoughts that cause fear to parents of ASD children cross their minds occasionally and will linger because the future will inevitably come for them.

It is normal for parents of neurotypical children and parents of children with disabilities to have future anxieties because they all want them to be secure and safe in their lives later. However, studies reveal that parents of children with developmental disabilities (DD), autism included, have a much higher level of anxiety and stress. One hundred sixty-seven parents to children with developmental disabilities (dd) and 103 parents with typical development have completed the Future Anxiety Scale FAS1 and results show that parents of DD have much higher future anxiety about their child's future health and quality of life. The group of parents of children with DD without a professional career is at risk of having the highest level of FA (Bujnowska et al., 2019). Parents develop anxieties stemming from their constant worries about everything they might do or what might happen to them. This is more common among them than anyone can realize it.

An article from Healthline, contributed by a teacher mom who has twins, and one who has autism, talks about the common triumphs and fears of raising a son under the spectrum. She indicates that she often knows her son, who is normal, will figure out how to solve his problem, but she cannot fully have peace of mind regarding her son with autism. She worries about his

uncertain future, if he will communicate well with others, how he will transition from one stage of life to another if she should just let him do his thing if he understands that he is loved, and what happens when she dies. None of these fears apply to her other kids. For her, parents' fears of ASD children may not be justified, but it certainly gives them resilience and will be the best armor in their determination to do what is best for the child (Thorpe, 2018).

All participants in this study explained how they take every opportunity to have teaching moments with their children. It stems from the concern that they want their child equipped with skills necessary for independence and survival, especially when they might pass their child ahead someday. From the previous theme discussed, they disclosed their constant worries for their child's future when they pass, even if they have relatives and other children who are truly concerned and love their child. This need for them to continuously teach them anything and everything under the sun stems from that anxiety, and they need to see for themselves while they are still around that their child demonstrates their practical life skills. It may not just make their child more independent, but it also eases their worries.

The sad realization is that autism, even when adults may need guidance now and then from their families often, spontaneously haunts them. It poses a big fear among parents because they know they might not live long enough to be around for their child's lifetime, so they must ensure they arm their kids with the right attitude and capabilities to fend for themselves. This is the most realistic goal for their child. Parents have high levels of worrying and stress when planning their children's futures (Liu, 2012). One common goal of parents of children with autism is for them to live independently and function as adults in their environment. Training them with necessary adaptive skills and watching them do it reduces the amount of assistance given to them, and this reassures parents that they can stand on their own in the future.

One of the most important responsibilities of parents is to teach their kids to be independent adults. However, parents of children with disabilities know they may never be able to live completely on their own. According to Lao (2021), a sped program and curriculum consultant, a common tendency of these parents is to hover over their children when they perform tasks done out of habit. Teaching them the right skills and independence will make them resilient. Although children with ASD often receive therapies, treatments, and special programs from the school, the hands-on involvement of parents in educating their children in different developmental aspects remains a crucial factor in their growth.

Parents' active participation in different programs and implementing them for their children is considered by experts an important factor in the long-term education of children with ASD. It is generally accepted that the family, especially the parents, are the key factors in the different domains of development of the child with ASD and that parents are even considered the "co-therapist" (Christier & Hall, 1993). Successful intervention happens when parents continue the education they learn from the programs. Since autism is a complex, multi-faceted disorder, parents use different techniques to address the pressures of raising a child with ASD (Chaidi & Drigas, 2020).

The success of an ASD child's development under different domains requires the constant dedication of his parents. Globally, parents of ASD individuals know they are the main caregivers, and no one has better strategies and intuition about the child than them. This is why parents in this study, no matter how inconvenient it is sometimes for them, would choose to do things themselves for their child, even if it means sacrificing something because their child comes first. A qualitative study in Iran also maps out the different levels of concern of parents of children with ASD, and that is the security of their child's future. According to the results, parent-participants in this study were found to constantly design, organize, and implement

interventions under the child's appropriate developmental stages, which aims to respond to their needs under the spectrum. It is reiterated that parents are needed to successfully transition the individual to adulthood and maintain their well-being (Ganjeh et al., n.d.).

### **Theme 2: Difficulties and Struggles of Parenting a Child with Autism**

All participants in this study admitted to their child having very difficult behaviors and had been put through a lot of stress at home and in public. It has tested their patience, and they have developed many ways to handle these behaviors. These acting-out behaviors are not usually seen among neurotypical children, so many people do not usually understand what is going on, and parents receive judgmental stares and comments regularly. Many of their experiences dealing with their child's meltdowns were borderline traumatizing and beyond embarrassing for them. Nevertheless, parents do not run away from the responsibility of handling their child during these difficult moments and trying to de-escalate the situation.

The burden of trying to manage these behaviors of children with autism greatly impacts the family, but most especially the parents because they are the main handler of the child. They have tried different techniques, and sometimes they might not work because their behavior management strategies might not be under the context of ASD. According to the study "How do Parents Manage Irritability, Challenging Behavior, Non-Compliance, and Anxiety in Children with Autism Spectrum Disorder", mothers parenting children with ASD spend 50% more time giving different types of scaffolding to their child compared to regular parents. The result suggests that complex parenting techniques are always done by parents handling their difficult behaviors (O'Nions et al., 2018).

Parents of ASD are said to suffer more and have significantly higher stress levels in dealing with the behaviors of children than parents of regular children (Abd Kadir, 2020). On top of all the regular parenting challenges they go through day by day, parents of children with autism still must deal with this kind of autism misbehavior which tires them to the bones continuously. This parental fatigue they have because of the constant dealing with the behavior can cause impaired functioning to such a degree that normal activities can be overwhelming for these parents (Bennie, 2017).

Although many people will soon realize the child has an impairment and the parent is just doing her responsibility, it is still very demoralizing, traumatizing, and embarrassing for these parents having to deal with this daily reality, and to add to this, nobody can help them. The parents in this study are not alone in this experience. A mother from New Zealand, Toni Brown, shares her embarrassment as a mother to a child with autism. Aside from being humiliated by her son's meltdown during a therapy session and was asked to leave when her son attracted more attention and would not calm down (Grigg, 2020). These behaviors embarrass parents because judgmental stares burn through them as they struggle to handle their children.

More research suggest a majority of parents experience this stigmatization globally. Other disabilities are more visible to people, such as hearing or sight impairment, physically handicapped, and genetic disabilities, so people are more understanding if they show unusual behaviors. According to social worker, Nosal (2015), since autism spectrum children generally do not appear different from neurotypical children, they get disapproving stares and unsolicited remarks. People think the child is too old to be acting out over the top, and these people embarrass parents, making them feel incapable. Eventually, parents would think about just avoiding places to avoid these parent stigmatizations by the public.

Just like other must-have skills in being parents to a child with ASD, patience is one of them that develops as time goes on. Pushing your patience beyond the limits regularly will enhance it more and even more. A study assessed parents' burdens, psychological stress, and coping resources. Results showed that the parents gained benefits from their parenting experience and to name they are changes in life priorities, growth in faith, patience, and self-control (Picardi et al., 2018).

Being stigmatized is one of the most painful experiences a family with a handicapped member can ever go through, especially if it comes from people, you know, and it happens during random times. Parents in this study had countless of these difficult public encounters, and it happens many times that the public reaction is already stereotypical. Encounters are so frequent that the stigmatization goes unnoticed. According to a recent review, parents of children with ASD often encounter varied forms of stigma (Mitter et al., 2019). Specifically, parents of ASD usually experience courtesy stigma, meaning it comes from the public directed to them, stemming from their lack of understanding and misconceptions about the parent's handling of the child stigmatized by others. When parents go through courtesy stigma experience repeatedly, they develop affiliate stigma, which makes them even more upset about their affiliations with their child with ASD; hence they perceive negative emotions toward themselves (Mak & Kwok, 2010). Many people do not realize the amount of trauma and damage they do to the family of these children whenever they give their unsolicited advice.

Another effect of this is children with ASD will have a lesser chance to participate or experience the regular way of life in the community, which is every parent's goal for their child with ASD, a sense of normalcy as much as possible. Many thoughts go through parents' minds when they experience being discriminated against and put down because of their child, affecting their mindset. Stigmatization is also found to negatively affect their psychological well-being and, in the long run, affect their quality of life (Zhou et al., 2018).

Furthermore, a study indicates that discriminating and stigmatizing parents can greatly negatively impact their child's involvement in community participation (Ng et al., 2020). Like what the participants in this study experienced, people made them feel less of what they were as parents. Instead of feeling included and protected, parents felt quite the opposite.

In addition to the stigmatization they continuously experience, some participants have shared their concerns about bullying from their peers. Bullying kids with special needs is not anything new. There may be a lot of groups advocating for them, and there is public awareness, but it does not prevent it from happening. A report states that 46% of kids with autism in middle and high school are bullied, and some studies also show that 70% of kids with autism are bullied in mainstream classes (Verret, 2016). Much research has shown a consistent trend of peer bullying among children with ASD anywhere they come from. A study highlights the most frequently bullied kids with disabilities are those with autism and learning disabilities. The study showed that ASD and ID are most victimized verbally and emotionally by peers and that there is a positive correlation between bullying and the severity of autism. It means that the more severe the child with autism, the more likely he will be to be bullied, and incidents occur in the absence of teachers (Eroglu & Kilic, 2020).

Other than parents avoiding social situations to prevent awkward moments between them and the crowd, they can also pick up the sense of being unwelcome in some situations. They know if that situation or place is safe for them and their child, so they can choose to be there or not. In one of the largest studies of Dr. Ruth Fischbach, with 502 parents in the study, more than 40% of the parents chose to isolate themselves from friends and families because of their child's behavior. There were also, 32% of them reported having been excluded by people

in many social events and activities, and 80% of them admitted that this kind of stigmatization has made their lives very or somewhat very difficult (Kinnear et al., 2016).

No matter how many individuals with autism one has encountered and how many times they have learned something new about autism, people will not truly understand how life is for them and their families unless they live it. Autism is familiar to everyone, but knowing and understanding the spectrum and how their families raise them is different. In a study of 259 participants, more than half were married, educated to a university degree, and employed. When asked if they knew about autism, 80% responded positively, but when asked further to rate their degree of knowledge, 41% felt it was very weak (Alsehem et al., 2017). This proves that the public has a few percentages of people who are aware of the deeper knowledge of autism, which results in a very weak public awareness about the spectrum hence the lack of understanding of the individual and what their family is going through.

In India, autism awareness is also severely lacking, and the incidence is ever-growing. Admittedly, the autism awareness level is very low, which is 12.6% only among the participants, compared to the US, which has a level of 100%. This is not due to the low prevalence in their country but to the lack of awareness and misconceptions among the population (Kapoor, 2019).

Parents in this study emphasized how much of their best was exerted many times in raising their children and tried to understand them. A parent knows when she is doing her best in parenting a child with autism and if she has given her all. However, no effort is enough for others when the child comes with difficult behaviors, and others lack understanding of the spectrum. According to a solicitor Julie Burton, parents are often blamed for what others perceive as bad behavior attached to autism. She has also lost count of the number of parents who have been blamed for their child one way or the other and have received a lot of suggestions from people to do this and do that (Rees, 2017). The blaming game on parents is nothing new. There were some theories between the 1940s- 70s trying to explain the possible origin of autism, known as the "Refrigerator Mother Theory," which suggests that the mother's coldness and emotional distance may cause autism, heavily hinting that the parents, mostly mothers, influenced the spectrum. Many mothers were reported to be angered and resented this theory which made them feel that they were the cause (Cohmer, 2014).

Any kind of disability in an individual requires services and other amenities that come with a cost. Not only do the participants in this study have claimed it is financially draining, but many acquaintances of the researcher and articles have repeatedly pointed out that the needs of an ASD child caused financial constraints in the family's income. All the participants look back and share how they struggled to pay for all the services their child needed and, simultaneously, had to make ends meet for their family. Even after they have sacrificed their careers and settled for something lower, the doctor's fees, constant therapies, medicines, transportation to get to centers, replacing destroyed items at home, specific food that the child only prefers due to their sensitivity and preference issues to food to name some had to go on being paid. There are many other typical costs in raising a child with autism; all parents know these well.

Across the globe, families of these children similarly go through continuous financial burdens. In a study from China on the financial status of families who have children with ASD, the result yielded increased odds of interference with parents' employment. It also decreases the household's income (Ou et al., 2015). In another study on the challenges of mothers raising children with ASD, aside from the stress on mothers' mental well-being and social life, the result also highlighted the financial concerns like an economic burden stemming from the need

to cover payments for autism-related services. The high maintenance cost of raising the child contributes to parental fatigue (Papadopoulos, 2021).

Parents have claimed in previous themes of this study the difficulties in understanding, coming up with more effective techniques, and struggling with autism stigma because of their child. If they have brawled with ways to devise an absolute strategy in handling them or perhaps had a method in decoding what they want during meltdowns, other people left to look after they struggled many times over. The participants in this theme shared the difficulty of entrusting their child to someone close to them because the child's behavior will worsen, or the caregiver simply gives up on them and the child. The people who watched them while their parents were away could not understand the triggers of their behaviors and meltdowns and hence did not know how to manage them. Not only do they have a hard time, but parents also admit to not having any peace of mind when they are away because they know the caregiver and the child will struggle with each other.

Participants in this study claim it is never easy to find someone who can take care of the child, like when they must do other things like do chores somewhere or be at work, and worse, is when they must start over again with their child and reset them to control the effects of having someone look after them. When someone takes over the responsibility of looking after a child with autism, it becomes challenging for the caregiver and the child. They, too, become stressed as much as the parents but most probably twice because they do not know the child's triggers and are not as versed about the nature of autism, unlike the parents.

It is usually hard to find a person who truly knows how to manage or control a child with autism, aside from parents, and those who attempt to do it get beyond exhausted and quit. An article from Healthline said that because of common behaviors of autism, such as self-injury, aggression, and extreme meltdowns, a lot of babysitters in the community are not qualified to have the responsibility of looking after them. Even experienced older babysitters cannot look after them. The non-verbal communication tendencies of autism will often raise trust issues and bump an otherwise very qualified caregiver because of the absence of parental comfort (Walter, 2021). It is an extremely daunting task to find the right person to look after a child with autism because there are so many concerns attached to it that you do not see when caring for a neurotypical child. Many caregivers may face many problems when the child is under their care, ranging from stress, restriction of other activities, anxiety, and diminished physical health (Tathgur et al., 2021).

### **Theme 3: Seeing the Silver Lining in Being Parents to a Child with Autism**

All participants in this study have a degree and had good careers, but they had to make sacrifices for their children. They also chose to be with their child and be hands-on in raising their children instead of entrusting them to someone else. Two of them happily started their jobs elsewhere, and it was looking up for them. However, they had to relocate and experience a downgrade in their careers because they had to choose a career that would allow them to be and see their child as much as they can; likewise have the time to bring them to therapies and be part of their child's development. The three participants were destined to leave and migrate somewhere with promising careers outside the Philippines. However, they had to give that dream up because they could not leave the responsibility of raising the child to someone else. They want to be there because they know the child will not develop well without their motherly dedication. Some of them even got emotional during the interview, not only because they felt they let a once-in-a-lifetime opportunity slip but because they know they are dedicated parents and the love for their child will come above everything else.

Even if raising a child under the spectrum suggests financial concerns, the economic burden for the family income, and extra fees for their treatments, their parents will still compromise their career goals and focus on the development of their child by devoting more time to them and being hands-on in raising them. In a study on mothers of children with ASD in Greece, they were not the only ones who had to make sacrifices. Some had spouses who also had a shift in career paths to fulfill childcare obligations daily. Some of them had to completely leave their jobs and be with their child, while others made career-related sacrifices such as looking for other employees that are more understanding of the demands of the needs of ASD individuals (Papadopoulos, 2021).

Many studies mention the common struggles and sacrifices parents made when the diagnosis was handed to them. Parents often put their jobs on hold or leave the work field. In another study, it was highlighted that when parents become constantly involved in the education and childcare of their children with ASD, they normally often withdraw from their old social environment and take a break from their successful professional careers (Kocabiyik & Fazlioglu, 2018).

Aside from the participants in this study, other parents of a child with ASD know that no matter how successful they are in their career and how hard they have built it up over the years will not feel like a triumph for them if their child has declined in his development. They have no plan b, even if they become the best employee. As one participant has said, a good career cannot save your child, nor will it develop him to his best capabilities when they become an adult. Research shows that autism parents, particularly mothers, would sacrifice their occupations to attend full time to their child with extreme and unique needs (Hellman, 2022). The family members know the repercussions of living with a member with autism in their household, and they are the ones who adjust their routines to help manage the child in any way they can.

In a study of couples who have a child with ASD, usually one stays home. At the same time, the other one works hard to meet the expenses for the child, many of whom admitted to quitting at the height of their career, like the participants of this study but in exchange for valuable personal gains. Additionally, this type of sacrifice resulted in growth and some personal transformation for the parents, and some admitted that when they gave up their careers, something good in return was given back to them in life (Reddy et al., 2019).

Generally, in studies of lived experiences of parents of a child with ASD, they will first mention mainly their struggles in life and strategies for handling their child. From having mild autism to having severe autism individuals, their parents will find a silver lining in raising them, which people do not often discuss. Parents recognize and celebrate every milestone, and just like the misunderstandings and other social stigmas they have received, others may also not fully understand their triumphs. The participants in this study share the other side of being parents to children with autism: experiencing the optimism and joys of raising them. They were vocal about what their child made them proud of and all the breakthrough moments, proving that all their sacrifices paid off and that their efforts did not go to waste. Parents are now seen as partners in different therapies by paraprofessionals. According to a certified speech-language pathologist, parents are no longer just observers during therapy sessions but are now seen as an essential part of the intervention. These programs recognize the parents as the "key players" in the program's success (Lowry, 2016).

One of the reasons why interventions become effective and enhance the development of children with ASD is the fact that parents know their children well, and implementing these techniques becomes an ongoing process. Every interaction becomes an opportunity for them.

They know how to modify and adjust their behavior management methods according to the mood and behavior of their child. Parents spend more time with their children than anyone else, and they know their children more than anyone else; hence they are the best implementor of any skills and behavior for the child. Nothing could make them more fulfilled than seeing their child improve in every development domain, especially if they played a big part in that training.

In a study that tested the association between parental input in the child's language and the language outcomes of children with disabilities, four studies with 47 children under the spectrum revealed that the length of parental input is strongly associated with positive language outcomes in them (Sandbank & Yoder, 2016). Other studies have also shown that developmental difficulties make good progress in the child's skills when parents are very involved. It also proves that parents are just as effective, if not more, than paraprofessionals and should play a key role in the child's development (Robert & Kaiser, 2011).

Since children with autism have no filter and cannot deceive them with their emotions, parents feel genuine love from them, which neurotypical children would not display to their parents. Here, all the participants shared how transparent their children are when showing their sincerest love and affection without verbalizing it. Socializing and attaching emotionally to someone may not be autism's strongest point, but they have ways of showing it, and when they do, parents know it is coming from their pure hearts. A comprehensive study showed a link between the genetic and environmental factors in an autism's behavioral pattern, including emotional tendencies. This means that parents' attitudes and emotions play a big influence on the ASD child's development, and one of them is emotional regulation (Crowell et al., 2019).

Another highlight of the parents' silver lining in their experience is their discovery of their strength, perseverance, courage, and resilience developed over the years. All participants shared how being parents to a child with autism has taught them valuable lessons and how it made them develop super traits. There was never a shortcut nor an easier technique in parenting a child with autism. This experience for parents continues to be very challenging worldwide. A study of parents of children with ASD developing resilience in life highlighted the interaction of parent participants in their social systems. Findings show that to have grown this mindset. The parents accepted the worse results in their micro and macro systems. They had to build positive relationships with themselves and outside through active interaction.

This thinking ultimately changed their social environment (Zhao & Fu, 2022). To cushion themselves and be able to cope with the difficult situation, parents continue the struggle. They have no plan B for it. Another study has highlighted the impact of such experience, and it found out from their participants and like the participants in this study, that they usually go through a positive self-transformation that fosters characteristics such as tolerance, perseverance, understanding, resilient, and patient (Reddy et al., 2019).

Despite the odds of raising a child with a complex condition, parents claim their child brings blessings to them and their families. Children with or without disabilities are all a blessing. Being different does not make them the least among the group. Society makes one believe they do not meet the standards of being normal. Many parents of children with autism realize that life is fair and there is balance in the universe. What is lacking in you will also be given back in other forms.

In some articles, parents worldwide can also attest to this phenomenon, like the participants in this study. Having a child with autism is not a life sentence or a lifetime of grief. One parent claimed, "the child has brought more joy into our family life than I could possibly describe. He is a real blessing in our lives, and we would be extremely disadvantaged if he was not part of it (Fessler, 2015). Another testimonial in a blog from a mother with a son with autism

has enumerated 23 different ways she was blessed in life since having her son. She reiterates that for a parent to make progress in this situation, the right mindset should be initiated by you, and it is entirely up to you to manifest this (Wright, 2009).

### **Synthesis**

No matter where you go and ask about parents' experiences of having a child with autism, they all have similar patterns of experiences and insights. Generally, if they talk about their experiences, the struggles and difficulties would comprise much of their sharing. The participants in this study did not hold back from sharing where they have fallen short as parents of their child with autism, and they will not deny their heartaches and their helplessness from the autism stigma they have received time and time again. On the other hand, they will also be very honest about their fulfillment and joys in raising a child with a complex condition. These negative, positive, and other insights comprise the stories of parents who have raised children with autism in their adulthood.

It will never be happy news for all of them once the diagnosis is handed to them, confirming what they have silently noticed and suspected. All of them will go through a series of emotions and pass through stages of grief and loss the moment they are confirmed with the dreaded news. There is a perceived overload on the part of the parents of these children and many other concerns. Although they may have different specific anxieties, they all point to the fact that they feel lost and will grope in the dark for a long time seeking the right help and worrying about how their child will be over the years. The core sorrows are associated with resolving grief and wondering how they can overcome them. They may ask the following: will he have a sense of normalcy? Can I seek the right treatment? Whom will I turn to if things get difficult? How much acceptance will we get from society? Can I afford his needs?

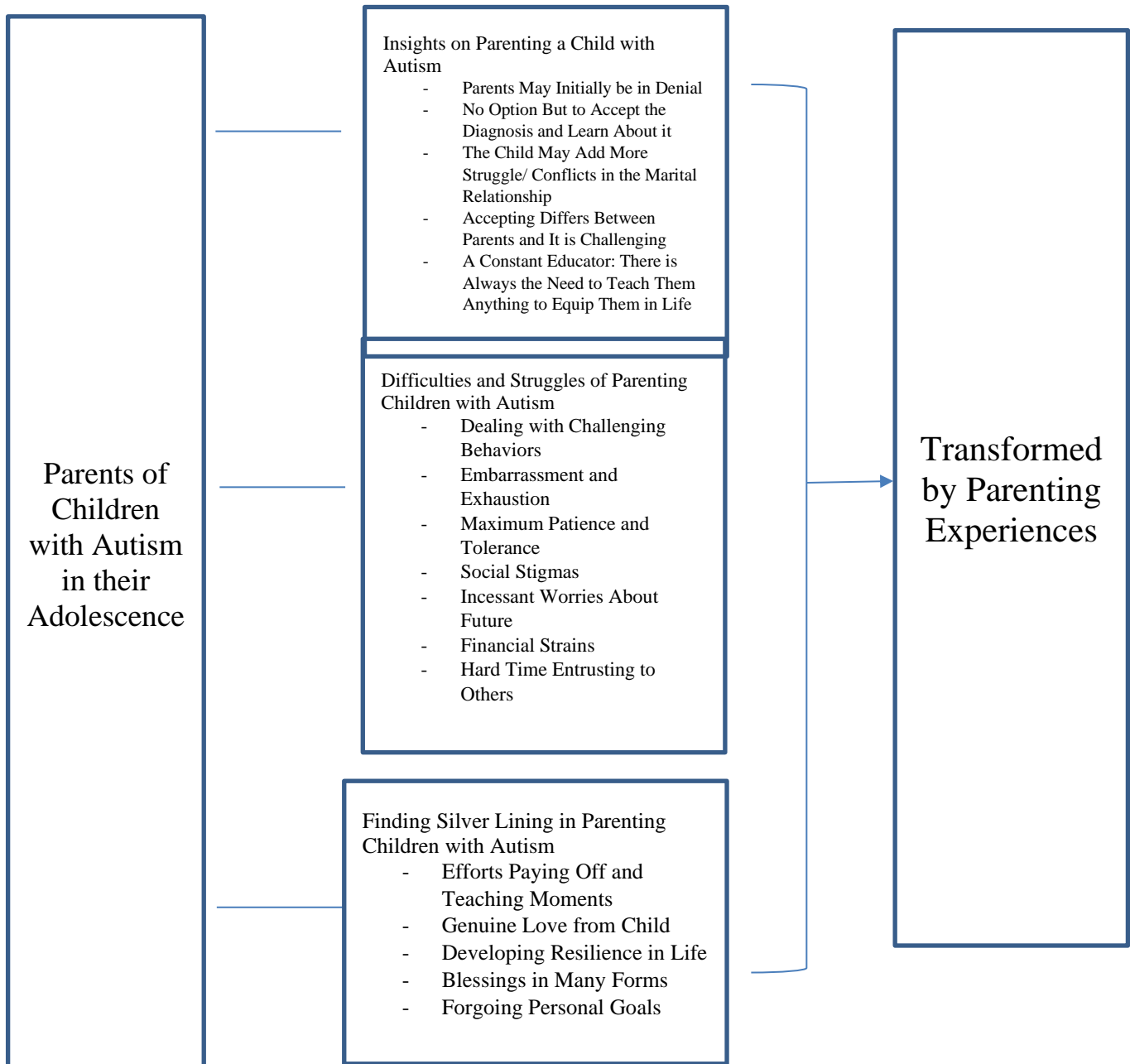
These worries from the beginning will continue to resonate throughout the different stages of the child's life due to the impact of grief of knowing and not knowing how they will take care of the child and how they will be in other aspects of their lives. Parental disbelief, distress, and anxiety are common at the time of the diagnosis and the many months to follow. Many studies show that parents of children with autism experience higher levels of stress, depression, and grief upon knowing the diagnosis compared to parents of children with other disabilities, and some may equate the sorrow to death but more painful because of the unpredictability and uncertainty of the future.

If you ask parents to share their experiences raising a child with autism, they will usually start with the struggles in different studies, but for every parent, it is not always a sad story. For parents, after all the challenges they experienced, there will always be a ray of light at the end of a dark tunnel. The early phases of their experience when they were just starting were mostly on the discovery of what it entails to raise a child with autism and face challenges that are quite new for them. The road may seem unclear ahead, and groping in the dark first is probably the most difficult stage, but once they have adapted and gained more experience, they also grow and gain more wisdom.

They will also have many realizations and see the positive side later. The positive contributions and positive outlook come from a group of parents who have children with ASD at older ages, like 18 years old and above. Seeing the silver lining in being parents to children with autism does not come at the start of the experience. It is gained and discovered over the years of being with the child. The unique and complex way of raising a child with autism is life-changing; parents are forever transformed due to their experiences.

The current study can be seen in the representation of the simulacrum. In the experience of parents having children with autism in their adulthood, they will start with their insights on having a child under the spectrum. Next, different forms of struggles arise as they bring up their child, and lastly, they will have realizations and discover the silver linings of having a child with autism.

**Simulacrum**



**Figure 1.** Transformed by Parenting Experience: Perspectives, Challenge, Optimism of Parents of Children with Autism Spectrum Disorder in Their Adulthood

**CHAPTER III**  
**SUMMARY AND CONCLUSION**

## **Summary of Findings**

After the interviews, the qualitative data yielded three major themes with several sub-themes under each theme, narrated intricately about their experiences raising children with autism until their adolescence. The themes that emerged are most common among the participants.

The first theme is insights on parenting of children with autism in their adolescence with five sub-themes; parents may initially be in denial, with no option but to accept the diagnosis and learn about it, and the child may add more struggle/ conflicts in the marital relationship, accepting differs between parents. It is challenging and a constant educator: there is always the need to teach them anything to equip them with life skills.

The second theme is the difficulties and struggles of parenting a child with autism with seven sub-themes; namely, parents face a variety of overwhelming challenging behaviors, caregiver embarrassment, and exhaustion on being hands-on parents, maximum patience, and tolerance is exerted, facing different types of social stigmas, having incessant worries and concerns about the future, facing inevitable financial strains, and entrusting the child to others is a problem.

The third theme is seeing the silver lining in being parents to a child with autism with five sub-themes, namely seeing their efforts paying off through the child's development and experiences becoming teaching moments for parents. Parents experience genuine love, develop resilience, become braver in life's trials, receive blessings in many forms, forgo personal career goals, and gain valuable life lessons.

The experiences of parents in raising children with autism are like no other, what parents of regular children do. Their struggles are incomparable to theirs. They are subjected to so much stress daily. No matter how uncertain things are for parents from the beginning of this journey, they will face and bear all the stress, the social stigma, the sacrifice of self-goals, difficult behaviors that will test them beyond their threshold, and financial worries because there is no plan B. Whatever comes their way, they will not give up on their responsibilities to their child and soldier on with being the best parents they can be. Their experience will transform them into the best version of parents they can be and develop resiliencies and courage beyond their capacity.

## **Conclusion**

This phenomenological study gives a common picture of the parents' experiences in raising a child with autism. It sheds light on their common problems with other struggling parents and their realizations. They have all struggled with mental and physical exhaustion in dealing with the child's difficult behavior, felt humiliation and autism stigmatization, experienced a decline in social life or a rift in a relationship with people, faced inevitable financial struggles, and sacrificed their self-goals and needs for their child. They are overwhelmed with incessant concerns and worries for their child in many aspects, usually daily. Commonly, even if they have trusted family members, they fear for the child's future, so they make it a habit to impart any learnings to them. Parents may rest in seeing their child develop practical life skills that will give them a sense of independence and indicate that they can at least fend for themselves when they are no longer around for their child.

Although bound to incalculable battles routinely, their experience is also their best teacher in life. The lesson from their experience equips them with the right problem-solving skills in difficult situations, whether old or new. Their unique struggles, which come in different

levels of severity, are unlikely to be like the usual problems other people encounter, which is why their child-rearing skills are misconstrued, and they are aware of this. They do not just give up on it. It is not an option for them in their case. Since their struggles come almost daily, their constant exposure to them makes them get used to problem-solving, and because of this, they develop resilience in life's struggles. They become braver in facing difficult situations, which must be dealt with no matter what. They would usually say there is no option to quit, nor is there a Plan B for their challenges because the problem with their child does not get fixed. It must be them. In their case, they go through a series of obstacles first, and the lesson comes afterward.

The realization of their resilience and silver lining in this role they have does not come easy and fast. It takes a myriad of exhausting, heartbreaking, humiliating, and frustrating experiences before they see their strong version and see another positive side; hence parents who have reached this point have older children. They have more insights than those who have just started their journey of raising a child with disabilities. For this reason, younger parents who are just beginning need to know what others have gone through and realize they, too, will prevail. Parents of children with autism need more support and understanding from everyone around them, and maybe one day they can be given some perks and privileges too, and not just the ones with disabilities because, after all, they are the ones raising them. Experience is the best teacher, but the hardest experience teaches you the hardest lesson. This is why parents with special needs children, especially autism, become transformed in life. Their experience brings out the better or the best version of themselves as parents.

### **Limitations of the Findings**

This study has several 5 participants from Negros, and each willingly did the interview online twice. There was no time limit to the duration, but each had an average of 1 hour per interview. Originally, each was informed that the platform for the interview would be through MS Teams; however, two participants could not access it for technical reasons, and their gadget was not set up to get through video calls, so the researcher and the 2 participants met through Zoom instead. This study cannot completely generalize the experiences of parents globally who have children with autism due to the limited number of participants, and the research method used was qualitative. In addition, the parents are all from the Negros Occidental province and are mothers. Parents in other provinces or countries may have more challenges not part of the themes. The scope can be enriched further if the criteria of the study were wider and insights of fathers or siblings may have been included, and the experimental method could have yielded more themes.

### **Practical Applications**

This study filled the gap and benefited parents with children with autism or any disability. Initially, they would feel uncertain about raising a child with autism and wonder what the best thing to do for their child is. When they encounter studies like this, they will learn the common patterns of experienced autism parents, navigate clearer on what to expect, gain useful insights, and have emotional support. They will realize they are not alone and that many other parents are going through the same thing. Aside from parents, other people who may be affiliated with the individual with ASD will expand their awareness of the transition of the child and his parents from the time of diagnosis until adulthood and focus on what it is like from the viewpoint of the parents raising them.

Other key beneficiaries of this study are teachers, especially the SPED educators who have first-hand encounters with them and their children. They should be more understanding and open to communication with these parents to have a good working rapport and perhaps ease their anxiety about leaving their child in school, just like participants expressed in this study. Showing empathy during their conferences and being hands-on with their children can assure parents that this may decrease their worries about their child in school.

The local government units, such as the Department of Social Welfare and Development (DSWD), should consider the parents with children with disabilities. Knowing that these parents struggle to juggle work time and time for children and the entire family, they may come up with ways to support them by offering programs for them or their child. The Department of Education (DepEd) can also benefit from this study. They can make sure there is always a place for children with disabilities in daycare centers all the time. In connection to RA 8672, wherein it is stated that there should be a daycare center in every community, they can ensure that these children are not denied in these centers. Lastly, the Department of Health (DOH) can also help these parents by offering mental health programs and other means of support for parents with children with disabilities.

In addition, the findings of the study may also be insightful to mental health professionals so they will have a deeper insight into the parents' struggles and factors that affect their stress levels, and this way, they can find ways to better address their problems and be given efficient support and counseling. Professionals who are identified to handle these troubled families will get the right training and give the appropriate therapy and programs to help the family cope with their struggles that will focus on their feelings and grief to improve their well-being, mental health, quality of life, and reduce parental stress.

### **Direction for Future Research**

Limited research has explored the experiences of parents raising a child with autism. This study will serve as a baseline for future research on lived experiences of mothers of children with autism. The patterns and other findings about their experiences would be helpful to other parents who are just starting their journey to have better adjustments in their life and other encountered struggles. This is also significant to future researchers who wish to tap into the related topic related, such as exploring other struggles of parents who have children with other disabilities aside from autism. They can use this as a reference to know the basic struggles and emotions of the parents and perhaps enhance it with their studies. Future researchers can interview parents or families outside the Negros Island. Other research methods besides the qualitative approach may yield other unique insights in future studies.

There could be possible changes or progress related to the study, and future researchers can continue the topic with different or better findings if they go beyond the scope of this study, such as having more participants, choosing fathers and siblings to interview, and considering other disabilities. They can recognize the limitations of the current studies on this topic and may add significant revisions for better public involvement.

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