

## **Nurturing Teenagers with Special Needs: As a Basis for Government Intervention Programs**

### **ABSTRACT**

#### **Background**

Compared to parents of average children, parents of autistic children experience higher levels of stress and endure various health issues.

#### **Aim**

This study aimed to look at parents' experiences of nurturing teenagers with autism in San Fernando, La Union, The Philippines.

#### **Methods**

This was a descriptive research study. The study employed a mixed methods approach to explore (in-depth) parents' experiences using both a questionnaire and an oral interview. Data were obtained from 8 parents of children with autism who were chosen using the purposive strategy. Three specialists in the profession evaluated both the questionnaire and the interview guide. The information gathered was examined using descriptive statistics such as frequencies, percentages, and themes. Following the questionnaire, a face-to-face interview was conducted to explain the goal of the inquiry in accordance with an interview methodology expressly created for that reason. The parents' exact body movements, gestures, and facial expressions were also studied to analyze underlying emotions.

#### **Results**

The results found out that most of the teenagers' parents were female (62.5%), most of the respondents were within the 31–35-year age group (37.5%), and three were separated from their spouse (37.5%). Most of the parents had a college graduate degree (50%). The four major themes derived nurturing teenagers with special needs: as a basis for government intervention programs were done through intelligent transcription, revealed the Parental/Guardian Involvement, Challenges of Parents/Caregivers, Coping Mechanisms of Parents, and Special Road.

#### **Conclusions**

Parents of special-needs teenagers must enhance their nurturing of their children while homeschooling and become smarter and more essential to manage the problems they face. A parent-school relationship is believed to be crucial for raising a special-needs teenager.

**Keywords:** Autism spectrum disorder, Nurturing teenagers, family support, government intervention program, special journey.

### **1. INTRODUCTION**

Education plays an essential role in the development of a country. If a country does not have proper education, it may be left behind by other countries that support education [1]. Many factors affect the education system. Culture, technology, and economic matters impact the education system. The regulations made by the government affect how the education system works in a country. Education is essential in human life. And as time goes by, the method of schooling changes dynamically to meet the needs of human beings [2].

Special needs are a phrase that covers a wide range of illnesses, ranging from those that resolve quickly to those that will be a burden for the rest of one's life and from very moderate to profound. Teenagers with special needs may have a variety of developmental delays, medical issues, psychological disorders, and/or congenital conditions. These specific requirements necessitate modifications so that youngsters can realize their full potential [3].

Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterized by significant challenges in community interaction, communication, restricted and repetitive interests, and behaviors. The word 'spectrum' is used because the span and stringency of the problems people with an ASD experience can vary widely [4]. There appears to be an increasing number of children receiving a diagnosis of autism spectrum disorder (ASD), and children are now being diagnosed much younger [5].

In the United States, there has been a significant rise in the number of children reported to have specific special needs (ASD) within the last two decades, since the U.S. Department of Education first recognized it as a disability in 1991. This is mainly due to the increase in public awareness and education of ASD and the development of better diagnostic protocols, leading to an increased need to help those children and their parents. According to the Centers for Disease Control and Prevention [CDC] estimates, one in every 68 children in the United States has one particular special need (ASD). Autism is four and a half times more likely to occur in boys than girls. When looking at the history of ASD, it is a relative disorder that still has many unknowns [6].

It's been proven that caring for a teenager with a developmental handicap causes more stress than caring for a youngster with typical development [7]. The birth of a disabled child produces tension in the family, particularly among parents, impacting the parents' quality of life. It is more difficult for parents of children with impairments, such as those diagnosed with autism spectrum disorder, to care for them than for parents of typical children. Given that chronic stress has been linked to various physical and mental health issues, parents of children with ASD have been reported to have lower health and more diseases than parents of healthy or normal children [8].

Being a parent or family member of a person with autism comes with unique challenges and heartaches. Bullying and exclusion are only some of the situations many faces. Sustainable development can only be attained if the needs of the most vulnerable people in society are met. The national and local governments have made significant strides in adhering to stipulations of the United Nations Convention on the Rights of Persons with Disabilities [9].

Parents of non-disabled children, when compared to parents of children with autism spectrum disorder (ASD), exhibit more significant levels of stress and lower physical health [10]. The parenting stress experienced by parents of a child affected by ASD appears to pose a greater risk to the parents' psychological and health-related quality of life [11].

Despite the prevalent research on autism, few studies have investigated this disorder's effect on the child's parents. Autism, at its very core, makes intimate familial relationships extremely difficult to develop. A condition inherently changes the parent-child relationship: communication is impeded or impossible; intimacy can be a challenge, and child self-injurious behaviors may make a parent feel frightened and helpless. Parents of children with autism have higher stress levels than normal parents [12].

The DepEd Order No. 32, [13] demands a holistic approach and a stronger partnership among schools, households, and communities. Parents and teachers who nurture their children, help them with their homework, and provide tutoring using resources provided by the teachers do a better job of nurturing their children than those whose parents do not help them. Parents and caregivers must recognize their contribution to the success of their children's education, nurturing, and upbringing. It is important for parents to be aware of the impact of the pandemic on their children's academic performance and wellbeing.

During the COVID-19 pandemic, the Department of Education (DepEd) implemented "adaptive learning methods for learners" and received support from Save the Children Philippines, a group that promotes children's rights and welfare. It is a non-negotiable fundamental human right. Children should have continued access to education, even in times of emergencies such as the COVID-19 pandemic, a former Undersecretary of DepEd said, "but we must put in place children's safety, which is paramount, and make sure that they have a safe and inclusive learning environment" [14]. Teachers have the ability and resources to provide quality instruction without compelling recent learning strategies that must be gender-emotional and extensive depending on the COVID Risk Severity Classification in your area and your compliance with COVID minimal health requirements. They should incorporate psychological and socio-emotional support for learners at home during the pandemic utilizing alternative delivery modes [15]. Learning delivery alternatives such as blended learning and distance learning have been embraced in public and private schools. Many families find it challenging to nurture and educate their children at home during coronavirus school closures.

Hence, this study aims to investigate in-depth the experiences of parents of teenagers with special needs, as a Basis for Government Intervention Programs.

## **2. MATERIALS AND METHODS**

The study used a mixed-method research design. According to this method, mixed methods research is a study that involves both qualitative and quantitative methodologies. It enables people to create and associate their own subjective and intersubjective meanings as they interact with the world around them. The participants in this study included both parents, fathers, and mothers, or the guidance of children diagnosed with one need (ASD). Parents have at least one child diagnosed with a specific condition (ASD) enrolled in a Special Education (SPED) school in the City of San Fernando, La Union. The sampling technique used for this study was the purposive sampling technique. All eight (8) parents interested in voluntary participation in this study and having a child diagnosed with special needs (ASD) in the City of San Fernando, La Union, were used for this study.

A self-structured questionnaire followed by an oral interview with parents was distributed among eight parents of teenagers with ASD. The questionnaire was used to generate reliable answers from the parents, including demographic profiles; this study used a phenomenology approach to look at (in-depth) parents' experiences of nurturing teenagers with special needs (ASD) in San Fernando, La Union. The questionnaire was distributed to 8 parents with the help of a teacher in charge; retrieved shortly once the filling was completed, followed immediately by a face-to-face oral interview (Interview guide). The study's data were presented in frequency count, percentage, and table formats, generating some themes.

### 3. RESULTS AND DISCUSSION

The demographic data of the respondents revealed that most were female 5 (62.5%) of the 31 – 35 years age group 3 (37.5%), separated 3 (37.5%), And most of the parents had a college graduate 4 (50%) (Table 1).

Table 1: Distribution of respondents by Age, gender, civil status and HEA of the parents

Age	Frequency (f)	Percentage (%)
26 -30	2	25
31 – 35	3	37.5
36 – 40	1	12.5
41 -45		-
45 – 50	1	12.5
51 – 55		-
55 – above	1	12.5
<b>Total</b>	<b>8</b>	<b>100%</b>
<b>Gender</b>		
Male	3	37.5
Female	5	62.5
<b>Total</b>	<b>8</b>	<b>100</b>
<b>Civil Status</b>		
Single	2	25
Married	2	25
Separated	3	37.5
Widow	1	12.5
<b>Total</b>	<b>8</b>	<b>100</b>
<b>Highest Education Attainment</b>		
Doctorate Graduate	1	12.5
Master Graduate	0	-
College Graduate	4	50
Tech Vocational Graduate	2	25
High School Graduate	1	12.5
<b>Total</b>	<b>8</b>	<b>100</b>

#### Some of the Themes derived from this Study

The analysis of the transcribed responses of the participants, done through intelligent transcription, revealed the *Parental/Guardian Involvement, Challenges of Parents/Caregivers in nurturing Children with ASD, Coping Mechanisms of Parents, and Special Road*. We present salient quotes.

In this present study, the demographic data of the respondents revealed that five were female (62.5%), most of the respondents were within the 31– 35-year age group (37.5%), and three were separated from their spouse (37.5%). Most of the parents had a college graduate degree (50%). It implies that the parents and teachers of teenagers with ASD were knowledgeable and educated enough that they could nurture and care for their wards. The parents of these teenagers may have had the opportunity to read or listen to their children's teachers' teaching and encouragement. This agrees with Horowitz [16], who noted that parents who finished college degrees could efficiently work and make sure that their children were also knowledgeable about health in general and what was happening around them, knowing fully well that

their children were their future. In the same vein, Muhammed [17] pointed out that the role of parents is vital in developing and nurturing children in the way they should grow among their peers. Teenagers with educated parents demonstrated a higher level of knowledge and practice if their parents influenced their understanding and nurtured them in putting what they learned at school and home into practice.

### **Thematic Model for Nurturing teenagers with special need (ASD)**

To nurture and train their children with special needs (ASD). This also gives parents a better understanding of the types of support and potential interventions that they may require. Lastly, the colloquium will help develop an effective parent-school partnership to achieve positive educational outcomes specifically for teenagers with special need (ASD) at this time of the pandemic crisis.

### **Involvement of Parents/Guardians in Home Schooling**

#### ***Parental/Guardian Involvement***

The DepEd Order No. 32, [13] demands for a holistic approach and a stronger partnership among schools, households, and communities. Parents who nurture their children, assist with their homework, and provide tutoring using resources supplied by teachers tend to do better in school than children whose parents do not have time to nurture or assist in their homework. Parents must understand their importance on the success of the process of education and on the nurturing of their children. It is important for parents to be aware of the impact of the pandemic on children's academic performance and wellbeing.

Furthermore, Shourbagi [18] stressed the importance of parents and guidance's involvement in the nurturing of their children, as their participation in teaching their children has been linked to increased parental confidence in, and satisfaction with, parenting, as well as increased interest in their own education. This, in turn, prepares them to be ideal teachers and parents for their children.

### **Challenges of Parents/Caregivers in Home Schooling Children with ASD**

#### ***Unwrapping Transitional Difficulties***

Many families face unique challenges when it comes to nurturing and assisting their children during home assignments. It may be difficult to consider the role of parents in raising a child to the level of attending school, but Kidd [19] found that parents, particularly mothers, can provide their children with an education that is suited to the way in which they learn. She further discussed that mothers also could control their child's environment to enable learning to take place.

The disruptions caused by the health crisis cause significant changes in the routines of teenagers with autism. The transition from studying in a four-walled classroom to confinement in their own homes, with their parents acting as both the teacher and a classmate, is a significant change in the children's daily school routine. Transitional difficulties in rules and authority, schedules and procedures, behavior management, and parental worry and stress fall under this domain. The application of rules and routines helps them engage more successfully in activities and prevents problem behavior. As a result, imposing rules and exercising authority can be difficult for parents because their children are already accustomed to attending school with the teacher exercising authority and enforcing rules during the learning process. The teenager's association with their teachers in school as educators was broken and interrupted during the transition. Thus, reinforcement is inconceivable, specifically in the scheduling of activities and implementation of procedures, which eventually poses another struggle in nurturing teenagers with ASD. The National Autistic Society [20] described a meltdown as an intense response to an overwhelming situation. It happens when someone becomes completely overwhelmed by their current situation and temporarily loses control of their behavior. This loss of control can be expressed verbally (shouting, screaming, crying), physically (kicking, lashing out, biting) or in both ways. Meltdowns are not the only way that a child with ASD may express their feelings of being overwhelmed. They may also refuse to interact, withdrawing from situations they find challenging or avoiding them altogether.

Parenting stress refers to the perceived stress of the parent in reaction to the demands of parenting the child, and Fadare et al [21] suggest that the child's difficult behaviors contribute to the parent's negative mood via decreases in parenting self-efficacy. Since mothers of children with ASD experience higher levels of stress compared to mothers of typical children, their increases in parenting stress may reduce parenting self-efficacy, which in turn might lead to increases in anxiety and depression.

### **Coping Mechanisms of Parents**

## ***Acceptance***

According to APA Dictionary of Psychology [22], acceptance is a favorable attitude toward an idea, situation, person, or group. Acceptance occurs when a situation or scenario is acknowledged and accepted by an individual. It is typically used in reference to the acknowledgement and assent to a negative situation. Acceptance is the last stage of the Kubler-Ross Model which is also known as the five stages of grief (denial, anger, bargaining, depression, acceptance). Parents pointed out that their new responsibility during this “new normal” of education left them with no choice but to accept and acknowledged this current role of being teachers to their teenager at home. Preparing themselves, attending to their child’s nurturing through sitting and learning with the child manifests their acceptance towards the concept of homeschooling. Research shows that acceptance is an important trait in positive well-being.

## ***Positive Disposition***

Having a positive disposition means having an optimistic outlook and attitude towards life despite experiencing adversities. The parents were faced with a challenge of having multifaceted roles including homeschooling their children and they have look at it on a different perspective, During the nurturing challenges, the parents tried to figure out how to become positive, stay calm and move forward. Being parents to teenagers with ASD includes many challenges but it’s how they rise to overcome these challenges with strength and positivity.

## ***Time Management***

For parents wrestling with the demands of everyday life, time management proves to be a real struggle. The additional responsibility of nurturing and educating a teenager with ASD who has unique and special needs can be a huge task that requires a significant amount of time for parenting. According to the article "What is Time Management?" [23], time management is the process of organizing and planning how to divide your time among specific activities. It discusses how good time management allows you to work smarter and accomplish more in less time, even when time is limited, and pressure is high. Failing to manage your time damages your effectiveness and causes stress. Parenting is hard work and learning and keeping in control of their time makes their personal life and family life run smoothly.

Parnell [24] pointed out that having good time management in nurturing will give parents total and complete control over their child’s environment, education, and social experiences. This will also allow the child to avoid and minimize sensory triggers, as teenager with ASD thrive on routine and structure. Time management and structuring activities that work for the family's schedule will help the child and other family members do their best with the learning plan provided by the school while being safe in the confinement of their homes. More importantly, time management enables parents to increase their family time and gives them the opportunity to spend more time watching their wards grow and learn. Nurturing jobs for parents are more about creating safety, belonging, and acceptance than they are about academics.

## ***Support from Family Members***

The "new normal" in education has shifted toward parents nurturing their children, which necessitates a significant amount of time. This also calls for help and assistance from other members of the family. It is of importance to gain support and assistance throughout the home education process. Getting support from your family gives you time for other things that need to be accomplished and empowers you to be able to navigate the challenges of family life.

Moreover, many parents/guardians, in their quest to cope with the situation where they find themselves responsible for teaching and educating their teenager, adopt a style of consulting and connecting with the teachers in school and special therapists. This is the adaptive coping method of seeking social support as highlighted by Lai and Oei [25] in their studies. Going back to teachers and therapists to discuss their concerns about their teenager enlightens them and they can acquire additional learning and information on how to manage the nurturing process. This will ensure parents and teachers have an improved educational outcome for their children with ASD.

## ***Parent-School Partnership***

Family-school-community partnerships are a shared responsibility and reciprocal process whereby schools and other community agencies and organizations engage families in meaningful and culturally appropriate ways, and families take the initiative to actively support their children’s development and learning. Schools and community organizations also make efforts to listen to parents, support them, and ensure that they have the tools to be active partners in their children’s school experience [26]. Parents are the first educators of their teenager, and they continue to influence their children’s learning and development during their school years and long afterwards. Schools bear the important responsibility of nurturing and teaching future generations, and families rely on schools to lay the educational groundwork for their children's future. That is the importance of parents and schools working together in a partnership. The Parent-School Partnership refers to the collaborative relationships and activities between parents or families and the school.

This is consistent with the article by Perras [27], which states that educators and parents generally agree that positive, supportive, and open relationships between home and school, parents, and teachers, are desirable. Additionally, research has shown that parent engagement and successful parent-teacher partnerships result in improved educational outcomes for students.

### **Special Road**

The experience of having a teenager with special need (ASD) the autism spectrum greatly affects the lives of most parents. Prior to the pandemic, parents' daily routines included doing housework, going to work, tending to family needs, and driving their children to school. With the emergency health crisis, parents have now taken on the role of educators, guiding their teenagers through learning modules given by schools and online classes. According to the United Nations report, "the COVID-19 pandemic has created the largest disruption of education system in history, affecting nearly 1.6 billion learners in more than 190 country and all continents. Closures of schools and other learning spaces have impacted 94 percent of the world's student population, up to 99 percent in low and lower middle-income countries [28]. For the parents of teenagers with special needs, particularly ASD, finding a solution to the "new normal" education is a positive way of focusing on the child instead of dwelling on the challenging situation. Filipino parents' unique approach to surviving this new learning modality has given them a fresh perspective. Parents have become hands-on and have direct involvement in educating their children and this has become an opportunity for them to monitor their children's progress.

### ***Essential Learning methods***

Staying at home and not attending school creates a uniquely stressful situation for teenagers with special needs and their families. It is noted that the disruption can be particularly devastating to students with disabilities such as autism, who thrive on routine and regular schedules. Though structured home education is difficult in the transitional period, Cahapay [29] noted that parents have collectively voiced out that any form of education transpiring within their homes is important to the development of their children. Learning at home can be tailored to the needs of their teenagers and family conditions. So, learning activities are more focused. This is supported by Feeney [30], who reported that many parents of children with special needs are looking into home education as an alternative to education. Furthermore, he claims that home education is beneficial for children with special needs (ASD) and will provide them with the best learning environment possible. Narzisi [31] added that home-based learning will maximize a child's potential early on, without having to adhere to the usual time standards set by schools. As in the case of children with autism, who work and learn at their own pace [29]. Some people may think that teenagers with special needs should not be given duties and responsibilities at home, but UNESCO [32] indicates that it is important to note that the duties you entrust to them and the work they take up can contribute to molding them and helping them develop identities of their own. As simple as keeping their things safe, secure, clean, and cleaning the dining tables after having dinner, can be assigned as responsible tasks. This would help them develop a sense of responsibility. Small roles could also be given in each of the tasks performed by the elderly, as this would increase the confidence level of the child and help in the formation of an identity. This is supported by the Theory of the Hierarchy of Needs of Abraham Maslow, which offers a framework for how humans can thrive. When basic needs are met, self-actualization occurs, according to the theory. The love, warmth, and care provided by parents has made children respond positively, hence, making both parents and teenagers thrive and develop a sense of belongingness and a sense of being loved, therefore making the home education experience a special road.

## **4. CONCLUSIONS**

In light of the findings of this study, we conclude that the government and NGOs should support the parents of teenagers with special need (ASD) by receiving adequate training and support that will enable them to renew parent-school partnership learning continuity for teenagers with ASD and to provide various home-nurturing routines required for a child's growth and development essential for learning methods. The model crafted from the themes should be intensified among parents, teachers, and community stakeholders to nurture the practices for teenagers with special need (ASD).

## **5. LIMITATIONS**

In comparison to prior research investigations, the current study included several drawbacks, such as a larger proportion of parents participating in this study.

**Consent:** Written and verbal consent was obtained from the principal and parents of teenagers with special needs (ASD).

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