

A journey without a roadmap: A hermeneutic phenomenology of parenting children with autism spectrum disorder

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ABSTRACT

Introduction

Parents of children with Autism Spectrum Disorder (ASD) often face heightened levels of stress and health challenges compared to parents of neurotypical children.

Purpose

This study aimed to explore the experiences of parents of children with ASD in Dagupan City, The Philippines.

Methods

The study used a hermeneutic phenomenology approach to deeply examine the experiences of parents of autistic children, using the themes of the poem, "A Journey Without a Road Map." A total of 11 parents participated in the study, which was conducted using face-to-face interviews following a specific interview protocol. The researchers also observed the participants' body movements, gestures, and facial expressions to study underlying emotions.

Results

Four major themes from "A Journey Without a Road Map" emerged from this study, representing the systematic progression of the experiences of parents of ASD children from diagnosis to daily living. The themes are *blessing and burden*, *traveling on a rocky road*, *keeping on course in uncharted territory*, and *pleasures in the blind journey*. The researchers made extrapolations by interpreting the parents' expressions through thorough observation of their body movements, gestures, and facial expressions. Researchers had direct encounters with some parents of ASD over time, and the challenges they face daily are undeniable. They experience situations that require extra strength, devotion, and commitment, and face circumstances that test their ability to adapt and live like every other parent.

Conclusion

There is a need for the government or other concerned institutions to sensitize the general public about autism spectrum disorder, sustain this initiative, and establish a functional network of support groups for parents with autistic children. In addition, the process of gradually integrating ASD children into the society by ensuring they are trained and supported to perform certain jobs has proven to be effective in alleviating the burdens and distress of the parents.

INTRODUCTION

Autism Spectrum Disorder (ASD) is a lifelong developmental disability characterized by significant challenges in community interaction, communication, restricted and repetitive interests, and behaviors. The term "spectrum" is used because the span and severity of the problems people with ASD experience can vary widely (Faras et al., 2010). There appears to be an increasing number of children receiving a diagnosis of ASD, and children are now being diagnosed much younger (Charman & Baird, 2002).

In the United States, there has been a significant rise in the number of children reported to have ASD within the last two decades, since the U.S. Department of Education first recognized it as a disability in 1991. This increase is mainly due to greater public awareness and education about ASD, along with the development of better diagnostic protocols, leading to a greater need to help those children and their parents. Today, one in every 68 children in the United States has autism. Autism is four and a half times more likely to occur in boys than in girls. When looking at the history of ASD, it is a relatively new disorder that still has many unknowns (Centers for Disease Control and Prevention [CDC], 2016).

Caring for a child with a developmental disability has been known to contribute to higher stress levels than caring for a child with typical development (Ingersoll & Hambrick, 2011). The study of the experiences and challenges faced by parents of children with ASD needs to be explored.

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 face. 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 the stipulations of the United Nations Convention on the Rights of Persons with Disabilities (Autism Society of The Philippines [ASP], 2014).

Parents who are primary carers of a child affected by ASD often experience higher levels of stress and poorer physical health compared with parents of typically

developing children (Brobst et al., 2009). The parenting stress experienced by parents of a child affected by ASD poses a greater risk to the parents' psychological and health-related quality of life (Johnson et al., 2011).

Despite 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. It is a disorder that inherently changes the parent-child relationship: communication is impeded or even impossible; intimacy can be a challenge, and child self-injurious behaviors may make a parent feel frightened and helpless. Stress levels in parents of children with autism are higher than those in other parents (Hasting et al., 2005).

Parents of children with ASD are at high risk for "caregiver syndrome" or "caregiver stress," a condition of exhaustion, anger, rage, or guilt resulting from unrelieved caring for a chronically ill dependent (Catalano et al., 2018). "Caregiver burnout" or "caregiver burden" are additional terms often used to describe a state of physical, emotional, and mental exhaustion that is accompanied by a change in attitude, from positive and caring to negative and unconcerned, as a consequence of attending to the ongoing demands inherent in caring for a dependent individual (Killian, 2008).

ASD has changed the direction of life for some families in Dagupan City, Philippines. Some mothers have decided to take a unique education course to cope; some have resolved to divert to music therapy to help their autistic children. Every story of autism is unique in the Philippines as each parent traces the impact of finding out information about their child's condition ("*Field Observation*," n.d.).

METHODS

Research Design

The study used a Heideggerian or interpretive phenomenological design. According to this method, people create and associate their own subjective and intersubjective meanings as they interact with the world around them. Therefore, interpretive researchers attempt to understand phenomena by accessing the meanings participants assign to them (Orlikowski & Baroudi, 1991).

Description of the Study Area

This study was conducted primarily at the Stimulation and Therapeutic Activity Center (STAC) in Dagupan City, Pangasinan, Philippines. The city government-supported STAC provides free assistance and treatment to children with disabilities (CWDs). The children visit the center two to three times a week for their regular treatment sessions, which last for 1 to 1½ hours. Some beneficiaries with behavioral and physical deficiencies are now displaying progress after a series of rehabilitation treatment sessions (Sunday Punch, 2006).

Data Collection

This study used a hermeneutic phenomenology approach to deeply examine “A Journey Without a Road Map” of parenting children with autism and the challenges encountered by parents in the Stimulation Therapeutic Activity Center, Dagupan City, Pangasinan, Philippines, between 2017 and 2018. The method is phenomenological in that it involved a detailed examination of the participants' life world; it attempts to explore personal experiences—the challenges faced by the parents and their perceptions or accounts of the challenges and stress they face as parents of children diagnosed with ASD, as opposed to an attempt to produce an objective statement of the object or event itself. Data was gathered from our participants through semi-structured interviews related to children diagnosed with ASD to obtain information on their experiences and challenges.

Ethical Consideration

Researchers obtained a letter of consideration for this work from the Stimulation and Therapeutic Activity Center (STAC), Dagupan, The Philippines, where the parents of ASD children take their children for therapies and weekly schedules.

Study Participants

The participants in this study included parents—both fathers and mothers—or close relatives of children diagnosed with ASD, who are guardians of the autistic children.

Inclusion Criteria

Parents who have at least one child diagnosed with any form of ASD and are enrolled in the Stimulation and Therapeutic Activity Center (STAC) and Special Education

(SPED) department of West Central Elementary School I Dagupan for their studies and therapies were included.

Some of the Themes Derived from this Study

The following poetic expressions were used to bring deeper meaning to the understanding of the subjective experiences of these parents, and also for the child, as supported by Rajabali (2014):

A Journey Without a Road Map

This isn't happening

In this phase, I cannot find a meaning

How can this be? I keep asking

Without answers, I keep searching

I am almost losing my mind and I don't know if I can carry on

Especially when the doctor said there is no cure

With cares and worries, I cannot control

The way they look at you makes me cry

Yet for you, I paid the ultimate price

Sometimes your actions are disturbing

With familial relationships frustrating

And I can't even get enough funding

I love you more than the sun and moon

I will not give you up for gold

Each day you grow and learn and love

I'm grateful to God for each day we have

You are sweet and smart

Smart as a rocket star

With a heart pure as gold

You have enough love to give and it will never be sold

All these in my heart will I uphold.

I love you so much, my special one.

Data Analysis

We used Van Manen's steps of data analysis as cited by Munhall (2012). These are immersion, the aim of the inquiry, inquiry, and expressions, contextual processing, interpretive interaction, narrative, and final analysis. In these phases, we summarized the answer to the phenomenological question with breadth and depth.

RESULTS AND DISCUSSION

The study aimed not only to describe the experiences of parents of children with Autism Spectrum Disorder (ASD) focusing on challenges but also to interpret their experiences and perceptions. We interpreted their experiences with a focus on the challenges and their

coping mechanisms or plans that help them assuage the challenges.

Salient Findings

Four major themes emerged from this study, depicting a systematic progression of the experiences of parents of ASD children from the point of diagnosis to their day-to-day living:

1. Blessing and burden.
2. Traveling on a rocky road.
3. Keeping on course in uncharted territory.
4. Pleasures in the blind journey.

Extrapolations were made by reading meanings to their expressions through thorough observation of their verbatim, body movements, gestures, and facial expressions to uncover underlying emotions.

Blessing and Burden

The joy of having a baby is limitless, birthing the parasite that has invaded the womb for 43 weeks. However, the result of the diagnosis makes their joy dissipate as swiftly as the weaver's shuttle. These parents were entirely oblivious of the experience of parenting ASD children, just like every other mother. They never anticipated what was to come; therefore, the presence of a child different from what they anticipated elicited the following responses – subthemes: *Blocking Reality*, *Drowning in the Sea of Grief*, and *Stuck in the Depths of the Ocean*.

Traveling on a Rocky Road

We discovered that, like these parents, the journey is long and rough with no land in sight from the ocean. They face menacing threats of mental disorder. At this point, they deal with issues ranging from worries of the heart, when they cannot see any hope on the horizon thinking about their children's future, to the embarrassing consequences of their children going off the rails every time by acting weird. They also face black eyes crying for empathy, the social effect of the children's condition, which is usually bullying and stigma.

As to the effect on familial relationships, some have been strained due to the presence of an autistic child, making the parents sometimes keep their families at arm's length to show their devotion to the child.

Keeping on Course in an Uncharted Territory

They also had to deal with challenges and circumstances that tend to put their commitment to the test. Here, they pay the ultimate price by sacrificing their goals, ambitions, and lives to take care of the children. Most of these parents would have lived entirely different lives if their children were not diagnosed with ASD. Also, in the journey, they deal with their children's dire need for attention. At the same time, they deal with financial issues, having to economize and save to avoid drowning in debt. All these can be very burdensome, but the burden can be assuaged by providing proper resources and support.

Pleasures in the Blind Journey

We have come to understand, as Ralph Waldo Emerson said, that what lies before us is not as important as what lies within us in life. However daunting and menacing this situation is, these parents have something to smile and be grateful for. They found the coping mechanism at the point of their greatest trouble: the emotional implication and mindset. Someone said, "*making a road around the mountain makes a great idea, but making a road through the mountain makes a great man.*" These parents are making a road through the mountain facing them. They have to look beyond what they can see: the pain, the sadness, the grief. No matter how much trouble these parents go through, they can still remember something and smile. This could be the child's sweetness, smartness, or the rare innocence of their autistic children.

Guardians of children with autism spectrum disorder have experienced a range of emotional disorders, ranging from denial to distress, anxiety and worry, depression, discrimination, and social problems with their family members. Having a child who has ASD can have a tremendous psychological, social, and medical impact on the parents' lives. Many researchers have indicated a vivid link between increased stress levels and parenting a child with a developmental disorder, especially ASD.

Our interpretation of this study has shown that parenting children with ASD starts with an emotional roller coaster of both joy and pain and can progress with a high propensity towards mental illnesses, and continue with a phenomenon of ambiguity and joyful mystery, getting both a blessing and a burden. Still, most of the parents in this study shift their focus from the commitment to the

benefit. The parents do not feel sufficiently supported by the government despite the 20% discount for people with disabilities. They long for hearing ears and wish society would have a proper understanding of the disorder and see how unique their children are, including their special talents and gifts.

We are not surprised by the overwhelmingly positive outcome of most of the parents in this study. The Filipino people, as we know, have an inherently rich culture of family obsession: they primarily prioritize family over everything else. Therefore, this rich common Filipino culture has helped some of these parents cope with the situation. They accept their family members no matter how weird or different they are. They are eager to carry on their stoic responsibilities without grumbling and, probably, with occasional or situational complaints.

Looking at [Perry's \(2004\)](#) model, which has four major components: Stressors, Resources, Supports, and Outcomes, each of which is divided into two domains we discuss thus: Stressors are the major and minor stressful stimuli in the lives of parents of children with developmental disorders, including those associated with the child, for example, going off the trail, financial burdens, or perhaps seeing no hope on the horizon and other life stressors. The resources area consists of the personal resources of the individual parent(s) and family resources. However, most of them have the support of their families. The third major component of the model consists of the support the parent or family may receive from outside the immediate family, informal social networks, and legal support services. The outcomes in the model, in keeping with the "resource imbalance" tradition, may be thought of as what is left over after considering the primarily negative (but also potentially positive) impact of the stressors, mediated and moderated by the primarily positive (but also potentially negative) influences of the various resources and supports available.

This study's findings have been mostly of mental health concerns, like depression, anxiety, and worries. Mental Health is a new and emerging topic in Public Health. Mental health assesses an individual's overall mental well-being; this is undoubtedly directly linked and significant to the physical state of an individual. When a man is stable

mentally, he is equipped to perform optimally in society, at work, in the family, and with a good relationship with himself. The lives of parents with ASD are very complicated and ambiguous. It starts with joyful expressions of expectations after nine long months, the denial of their expectations, and the consequent reactions after admitting reality are usually grief and despondency. It continues with learning to live with reality, traveling on a rocky road: adjusting to the new life and challenges, and dealing with the difficulties that it brings along the way. Notwithstanding, it is not without its fun and joy, depending on the parents' resources and psychosocial level.

It is undeniable that these parents or parenting children with ASD generally come with many challenges. Distress and burdens are inextricable from their lives; some have managed some of these distresses to a level that obliterates the discrepancies between having an average child and having an autistic child. Nonetheless, gleaned from this study, the challenges they experience may not be just physical or evident to the public, but psychological and internal worries and struggles.

The parents first experience both a blessing and a burden; having a child gives them joy and a blessing, but an autistic child alters the expression of that joy. Like many other expecting mothers, they anticipate a bundle of fun, but what was to come will usually affect the pleasure.

The initial autism diagnosis leaves parents and siblings confused, and they may have a hard time accepting that the child/sibling they were anticipating is not the child/sibling they expected; they are in the process of blocking reality. All the parents in this study denied the fact at first, and of course, when denial is in play, the parents simply refuse to acknowledge the truth, no matter how apparent. This new transformation in their family impacts the family's relationships, as feelings of fear and worry encompass the family system. This assertion is supported by [Schaaf et al. \(2011\)](#), who said: "an autism diagnosis can be perceived as a loss for the family."

After this initial phase of denial, they usually graduate to another emotional level of depression. The grieving process associated with the birth of a child with disabilities is complicated by the parents' grieving the 'expected'

baby's death. This occurs at a point when the parents are drowning in the sea of grief. They are completely down with depression, which is "raising a child with autism is associated with increased family stress and depression" (Karst & Van Hecke, 2012).

We also realized that parents of children with ASD are at high risk for "caregiver syndrome" or "caregiver stress," a condition of exhaustion, anger, rage, or guilt that results from unrelieved caring for a chronically ill dependent, which is wholly supported according to CNN (2007). Guidance burnout and caregiver concern are extra tasks often used to interpret a state of physical, volatile, and mental weariness that changes attitude from positive and caring to negative and unconcerned as a consequence of attending to the ongoing demands inherent in caring for a dependent individual (Killian, 2008).

Seeing no hope in their situation is like being stuck in the depths of the ocean; with the cause and cure of autism still unknown, parents experience blame for their child's autism. Some fathers may blame autism on their wives, seeing them as "refrigerator mothers" (Neely-Barnes et al., 2011). They are forced to live in misery, bearing their crosses, sometimes alone and feeling ostracized and neglected. Meadan et al. (2010) acknowledged that the child's behavioral symptoms, such as impulsiveness, aggressiveness, and tantrums, produce feelings of grief, stress, and confusion. In summary, the first phase of their lives as parents of children with ASD can culminate in mental health problems. This is supported by Karst and Van Hecke (2012), who found that raising and supporting a child with ASD appears to have adverse effects on parents and families, regardless of the time since diagnosis. It appears to lead to a general decrease in parental well-being and an increase in mental health concerns. However, there is usually a constant transition from the initial oblivion and the consequences of adapting to reality, like traveling on a rocky road. Dealing with a child with ASD can be difficult for the parents; nevertheless, they have to travel down the road, no matter how rocky it looks.

The emotional, familial, social, and financial impacts of having a child with autism seem common among many parents or guardians, as supported by Nealy (2012). As posited by Hartmann (2012), having a child with ASD has

a considerable impact on a household. Parents and siblings of children with ASD suffer more stress and depression than those with typically developing children or even those with other disabilities. They do not see any hope on the horizon. According to Padden and James (2017), simply being the parent of a child with autism can greatly influence or shape one's identity. Some of these families encounter many stressors (both normative and non-normative) that are not directly related to the presence of a child with ASD. A study by Benson (2010) found that both child symptom severity and stress proliferation (i.e., the tendency for stressors in one area of life to produce stress in other areas of life) were associated with depressive symptoms in parents. In line with Perry (2004)'s model, a complete characterization of the stressors experienced by parents, such as work, finances, the presence of additional children, family structure, and other family issues, must be considered when conceptualizing how parents of children with ASD experience stress.

Another challenge these parents face is their children's unusual and not-normal behaviors. As opined by Werner (2004), the lives of persons in families with children with autism often revolve around dealing with the child's unusual behaviors. These behaviors may adversely impact family function. Behavioral symptoms recognized in children diagnosed with autism include hyperactivity, short attention span, impulsivity, aggressiveness, self-injurious behaviors, and temper tantrums. These, in turn, produce feelings of grief, stress, and confusion (Meadan et al., 2010). Davis and Carter (2008) also supported this by saying that the impairment of a child's ability to relate to others is unique to the diagnosis of ASD. Notably, this characteristic has been associated with higher levels of reported parental stress. Besides, some features of ASD are more severe than others. Ventola et al. (2007) found that children with ASD had noticeable and consistent impairments in socialization skills, particularly joint attention skills, and were more impaired in certain aspects of communication, play, and sensory processing when compared to children with Developmental Disorders (DD). Further, children with ASD were observably distinct from other children with DD in behaviors such as responding to smiles with a smile, joining adults in functional play, and initiating verbal and nonverbal requesting behavior.

Still, on the rocky road, they experience black eyes crying for empathy. Some parents are still concerned about their children's behaviors and tantrums, which have consequently put them in a vulnerable situation for stigmatization. From their explanations, some of these parents ignore the stigmatization, making society think they are not affected by it, but they are. They ignore it publicly but worry about it privately. Stigma is one of the most difficult aspects of public encounters experienced by parents of children with a disability. Stigma is a social construct defined as a mark of shame or discredit, characterized by guilt or disgrace. Components of stigma include labeling, stereotyping, separation, status loss, and discrimination (Link & Phelan, 2001). Parents of children with autism often experience stereotyping and negative public reactions.

Furthermore, this situation also affects other members of the family, making footprints of lovers disappear and straining relationships with other family members. As stated by Hastings et al. (2005), autism, at its very core, makes intimate familial relationships extremely difficult to develop. It is a disorder that inherently changes the parent-child relationship: communication is impeded or even impossible; intimacy can be a challenge. Although many parents of ASD children enjoy kind gestures and sympathy from other family members, the presence of an ASD child can also strain some familial relationships. One participant observed that she was completely not in tune with her family because of her ASD children. For her, it is because of the way she is raising them; for others, it is the feeling of shame, embarrassment, and disgrace that puts them at 'arm's length' with their family members. Relationship satisfaction acts as a buffer to the stress of parenting a child with ASD (Risdaal & Singer, 2004).

Still, on the journey, the parents owe it to themselves to keep on course in this uncharted territory, and this requires a lot from them. Apart from the challenges on the road, their commitment and strength are put to the test in this phase. The parents interviewed are living like sacrificial lambs, making sacrifices on the journey and paying the ultimate price. Their lives are rife with sacrifices, giving up their dreams and ambitions to give their children their full attention and affection. All that they do and live for becomes relative to the care of their

children; some of them have to take a new route in life: for example, some will only choose vocations that will allow them to help their autistic child, and not necessarily what gives them contentment and satisfaction. They lay their satisfaction and happiness on the altar of sacrifice for their children. Some mothers have decided to take a course in special education; some resolved to divert to music therapy to help their autistic children.

They also dread the constant hunger for the attention of their children. One of them described in a frustrating tone how she can't get a breathing space: "I can't leave him alone in the house. I always have to be beside him. It's hard because he can't express his feelings." Research shows that parents of children with ASD experience more stress than other parents, whether due to the stress of taking care of them or the sacrifices they have to make daily. Both formal and informal supports are important for these parents. Formal supports include those provided by an agency, such as family doctors, early intervention programs, and respite care providers. Families use formal supports for information and professional guidance. Informal supports refer to support provided by someone in the person's social network, such as friends, family, neighbors, or acquaintances.

Lastly, one of the major challenges or rocks they encounter on the journey is a financial challenge. They have to scrimp and save to avoid being saddled with debt. Therapy fees, feeding, accommodation, and expenses for extra needs can all pose a great threat to the financial capacity of the parents. Usually, this is the most challenging aspect of parenting children with ASD, but in this study, it is not the most challenging. This agrees with the report of Nealy et al. (2012) that the emotional, familial, social, and financial impacts of having a child with autism seem to be a common theme among many parents or guardians. Some parents in this study have financial challenges because the mothers cannot work; some are single mothers and still need to provide full attention for their ASD children, which does not eliminate the financial implications. The single mothers might be dealing with the emotional trouble of a husband who left—either by separation or demise—combined with the care for the autistic child, and this can constitute a great burden.

Nevertheless, while going through the rocky road, according to family stress theory, resources play an integral role in how families adapt to stressful circumstances. Perry (2004)'s model includes personal and family system resources as important elements that may affect the relationship between having a child with DD and positive and negative parental outcomes. Perry described individual resources as "personality variables and cognitive coping strategies and beliefs, as well as more demographic factors (such as education and employment status)." The presence of resources has made it easier for some of these parents to navigate the rocky road; parents who have wealthy family members or a strong and optimistic personality seem to see the rocky road as a piece of cake, while parents with few or no resources feel heavily burdened by the journey. The model also contains Stressors, the major and minor stressful stimuli found in the lives of parents of children with ASD, including those associated with the child, such as going off the trail, financial burdens, or seeing no hope on the horizon, as well as other life stressors. The outcomes may include what is left over after considering the primarily negative impact of the stressors, mediated and/or moderated by the primarily positive influences of the various resources and supports available.

Notwithstanding, some of these parents are very strong, boldly courageous, and have taken the challenge head-on. Some see this as an opportunity to show off their strength as mothers, even without a husband. Others have seen it as an opportunity to help young grieving mothers who are still in denial, using their stories to encourage them. Looking at *the pleasure in this blind journey*, it is undeniable that studies like this often show many emotional signs and displays, but these parents still have reasons to smile during the interview. Since the saying "life is what you make it" is valid, most of these parents have shifted the beam of light away from the obnoxious condition to turn it into a positive situation. They focus, instead, on the good aspects of these autistic children. This has developed in them an admirable characteristic and quality applicable to life—a quality we would love to have: the ability to look beyond one's present situation and see the ultimate instead of the immediate. Some have described their children as sweet as perfume, relishing good memories of the children's public displays of affection, emotion, and

compassion, such as would hardly be found among children without ASD. Sometimes it is in constant kissing or holding of hands, or even the total reliance some of them dread. Yet they feel joyful seeing this as a positive aspect of their experience parenting these children. The first participant showed so much emotion that she cried while relishing how her son would kiss her even in public, and another was so proud her son would always confess his love for her. These parents also adore the inherent innocence and simplicity of their child, describing them as having a pure heart. With great delight, they proclaimed how smart and intelligent their kids are, as smart as a rocket star, almost likening them to the great scientist, Albert Einstein. And of course, evidence shows that some children with ASD are usually exceptionally intelligent and dexterous. This is a positive side that most parents would be glad and proud to share. Some parents have been diligently creative with the situation, like dedicating a day of respite to the autistic child. That's the day they go out without work interruption. The situation that was meant to break them made them not only stronger but wiser, better, and happier.

Gray (2006) highlighted three strategies used by parents of children with autism: accommodation of the biological basis of autism, in which the parents accept that the disorder is a result of natural causes; resistance to the biological basis of autism, where parents tend to view autism as a consequence of external influences or forces; and the use of spiritual beliefs to understand the situation, which is based on beliefs in God and the conviction that everything is possible through faith. Other coping strategies include accessing information, withdrawal from social interactions, shifting expectations, and working towards inclusion and greater acceptance of the child (Gona et al., 2016). The majority of these parents adopt the accommodation of the biological basis of autism, spiritual beliefs, and social interaction as their coping mechanisms. Unlike the findings of some studies, however, like that of Padden & James (2017), many of these parents have the sympathy of society. They enjoy the luxury of support from families and friends, and even colleagues in the same situation. They are not marginalized; some only feel less supported by the government, understanding that this is a developing country with limited resources to cater to them. Few of them would be delighted to have a government-

standard facility to leave their children in the eventuality of their death, but some are skeptical of the ability of the government to properly take good care of their children if left in their care.

CONCLUSION

There is a need for the government or other concerned institutions to sensitize the general public about Autism Spectrum Disorder, sustain this initiative, and establish a functional network of support groups for parents with autistic children. In addition, the process of gradually integrating ASD children into the society by ensuring they are trained and supported to perform certain jobs has proven to be effective in alleviating the burdens and distress of the parents.

Recommendations

Experiences of the parents of children with ASD in San Fernando City have precipitated the following recommendations:

1. There should be a thorough and constant public awareness program about the concept of ASD. This can be done on TV, in radio stations, or in Barangay meetings to stop society from being naïve to the situation and therefore find ways to associate with the children with autism and help them integrate into society.
2. A functional network of a support group for parents with autistic children can be established by the government or any concerned institution. It could be an outreach arm of Region 1. This group can be sponsored by the government or stakeholders to bring about highlighted events and training or support necessary to help the parents.
3. The conduct of parallel studies is also recommended to look into the phenomenology of extending support to parents of children diagnosed with ASD.
4. A transition program started by SPED can be supported by parents of children diagnosed with ASD. In the program, all special schools and therapy centers must send some of these ASD children who are becoming adults and improving in their social skills to work with companies for some time. With

gradual improvements, they can become independent and full-time workers.

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