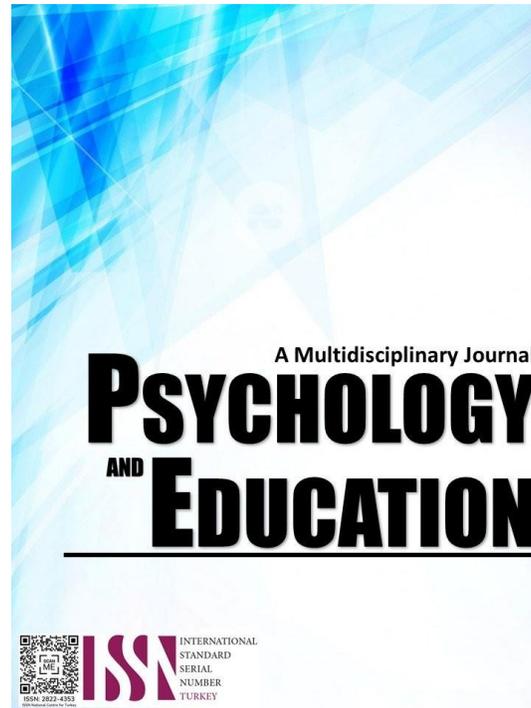


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PSYCHOLOGY AND EDUCATION: A MULTIDISCIPLINARY JOURNAL

Volume: 18

Issue 5

Pages: 489-501

Document ID: 2024PEMJ1684

DOI: 10.5281/zenodo.10916230

Manuscript Accepted: 03-15-2024

Stories of Parents Having A Child With Down Syndrome: In Narrative Inquiry

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Abstract

This study explored and documented the child-rearing stories of parents of a child with Down syndrome in the city of Iloilo. The qualitative study examined child-rearing experiences of parents with children having Down Syndrome, utilizing narrative inquiry to gather stories and insights. One family was primarily chosen with additional participants for triangulation. Through interviews and observations, the study aimed to understand the challenges, successes, and parenting aspects involved. The study addressed specific questions regarding parental experiences, successes and challenges, parenting features, and lessons learned. The findings highlighted the initial difficulty parents faced upon learning about their child's condition, eventually accepting it and supporting their child to overcome challenges. Successes included fostering understanding and patience, leading to the child's acceptance and growth. However, challenges such as caregiving responsibilities, illness, and financial strain were evident, aligning with existing research. Parenting aspects revealed a positive parenting style, balancing guidance and discipline while respecting the child's autonomy. This approach facilitated the child's development and reduced the severity of disability symptoms over time. Key lessons learned by parents included accepting their child's condition, improving parenting skills through acceptance, and realizing the importance of unconditional love and guidance in raising a child with special needs. Overall, the study shed light on the complex experiences of parents raising children with Down Syndrome, emphasizing the importance of acceptance, support, and positive parenting in promoting the child's well-being and development.

Keywords: *stories, parents, down syndrome*

Introduction

As described by Wilson (2013), a family is the most important social unit of society. It is not only the basic societal unit, but it is also the basic sexual unit, the basic communication unit and the basic child-raising unit. However, the process of child-rearing, in spite of its proverbial importance as a determinant of adult character, has not been much investigated by scientific procedures. Clinical studies of disturbed children, as well as experimental observation of normal ones have shown a number of important causal relationships between mother's child-rearing practices and the behavior of their children. Some personality characteristics of adults appear to be extensions of the effects of early experiences (Sears, Maccoby & Levin, 1985). Moreover, having a child with a disability in a family may have a positive, negative, or neutral effect on the family quality of life depending on individual family characteristics, type of interactions among family members and how each member functions (Turnbull & Turnbull, 2001).

Most of the research on child-rearing focuses on broad aspects of parenting, as proposed by Baumrind (1967) and Hoffman (1994), which may not look into the different aspects of parenting. Concentrating on the different areas of parenting may provide an opportunity to the parents to do a detailed analysis of their parenting style, and may give good insight on how good a parent he or she is.

In this context, this study found out the child-rearing stories of parents having children with Down Syndrome, the successes and challenges that the parents encountered, the lessons learned by parents in raising children with special needs and how parents raised their children in relation to their disability. The major aim of this study was to document child-rearing stories of parent having children with special needs in such a way that these stories can also help and give insights to other parents in similar situation. This documentation is necessary because there seems to be very little literature on child-rearing stories of parents having children with Down Syndrome in the Philippines.

Research Questions

This study explored and documented the child-rearing stories of parents of a child with Down syndrome in the city of Iloilo. Specifically, this study sought to answer the following questions:

1. What are the parents' experiences in relation to the disability of their child that are revealed in their stories?
2. What successes and challenges did the parents of a child with Down syndrome face while raising their child with special needs?
3. What are the parenting features and aspects that are revealed in the stories?
4. What are the lessons that the parents learned while raising a child with Down syndrome?

Methodology

This section presents the Research Design, Methodology, and Ethical Considerations involved in the study.

Part One, Research Design, discusses the method used in the study.

Part Two, Methodology, describes the respondents involved in the study, the data gathering instruments used, the steps of the research process as well as the procedures for data analysis. It includes four (4) phases: Phase One (1) - Selection of Subjects and Informants, Phase Two (2) - Data Collection, Phase Three (3) - Data Coding, and Phase Four (4)- Data Analysis.

Part Three, Ethical Considerations, identifies the ethical considerations in the study.

Research Design

The study focused on documenting child-rearing stories of parents of a child with Down syndrome through the use of narrative inquiry. The study was done through documenting child-rearing stories from parents to form themes for the study. Clandinin and Connelly (2000) defined narrative inquiry as a way of understanding experience. It is collaboration between researcher and participants, over time, in a place or series of places and in social interaction with milieus. An inquirer enters this matrix in the midst and progresses in this same spirit, concluding the inquiry still in the midst of living and telling, reliving and retelling, the stories of the experiences that make up people's lives both individual and social. Simply stated, narrative inquiry is stories lived and told. Cole and Knowles (2001) claimed that data are thematically interpreted and considered in relation to relevant discipline-based theories and represented in the form of detailed and rich life history accounts. These accounts represent both the researcher's interpretation of the research participants' lives, and the researcher's theorizing about those lives in relation to broader contextual situations and issues.

Participants

The research participants were the parents (the mother and the father) having a child with Down syndrome who lives in Iloilo City and who had first-hand experiences and knowledge about child-rearing. A pre-survey was conducted first before purposively choosing the participants. The researcher listed the names of parents who are raising their children diagnosed with Down Syndrome from the different schools in Iloilo City. The availability and the willingness of the participants to share information were also considered in the selection process. A set of criteria was developed in response to the need of the research problem. The criteria was made to qualify the participants in the study. The inclusion criteria for selection of participants are the following: the participants must be the biological parents of children diagnosed with Down Syndrome, parents who have children with Down Syndrome that able to send their children in school, parents who are living in Iloilo City and parents who are willing to share their experiences in child-rearing. The exclusion criteria for selection of participants are as follows: parents that are not biological parents of the child and those who serve only as guardians.

The researcher came up with one family as participants of the study focusing on both parents, the father and the mother, as suggested by the research panel. There were also peripheral participants selected to participate for triangulation purposes and to add more information needed in the study. The peripheral participants were the teacher, the neighbor and the brother of the child with Down syndrome who had known the participants for a long time and had been with the family along their child-rearing process.

Instruments

The study utilized two kinds of instruments: the interview schedule and observation guide. The first instrument, interview schedule, consisted of two parts: the personal data and the instrument proper. And the second instrument was the observation guide. The personal data was designed by the researcher to gather the vital information of the mother and the father having a child with Down syndrome such as names, address, ages, highest educational attainment, and occupation respectively. The number of children and the birth order of child with Down syndrome was also asked by the researcher.

The instrument proper contained the interview questions that have open-ended questions that provide broad parameters within which interviewees can formulate answers in their own words concerning to the topics specified by the interviewer. An interview protocol was used to assist them in collecting data.

An interview extended to the procedural level of interviewing and includes a script of what will be said before the interview, script for what the interviewer will say at the conclusion of the interview, prompts for the interviewer to collect informed consent, and prompts to remind the interviewer the information that he/she is interested in collecting. Interview protocols become not only a set of questions, but also a procedural guide for directing a new qualitative researcher through the interview process (Jacob & Furgerson, 2012).

The observation covered different aspects of child-rearing practices of parents that will be used to counter the statement of parents if they are telling the truth. In this method, the researcher observed the behavior under study in its natural setting, while attempting to avoid influencing or controlling it (Hockenbury & Hockenbury, 1997). Observation and analysis of the interaction of the parents and children around were also done. Through these observations and analyses, a good and clear idea regarding child - rearing emerged. This observation was used in the triangulation of data. The draft of the instrument was likewise shown to the research adviser for comments and recommendations. The final draft was made and validated by the selected validators of the researcher. Validators are chosen because of their expertise in research, instrument construction, and their role as good mentors. The instruments were further analyzed whether they were parallel to the research questions. The final interview question was then constructed with the approval of the research adviser.

Procedure

Data collection procedure was done using the instruments prepared for the purpose of the study. Data collection was done by means of documenting the focus interviews to the participants and actual observation. Interviews were conducted on the convenient time of the research participants. Observation was conducted through home visitations to the chosen family participants that lasted for 5 days. Typical interview was done for thirty (30) minutes to one (1) hour. The recorded interviews were transcribed and categorized into themes.

A basic principle of qualitative research is that data analysis should be conducted simultaneously with data collection (Coffey & Atkinson, 1996). This allowed the researcher to discern information on the focus interviews and observations, and to decide how these information will help in making conclusions in the study. The researcher categorized the data collected such as coding and thematic analysis of information gathered from the focus interviews; connecting themes through narrative analysis within an experience and between experiences; and using recorded notes and pictures to assist generating relationships in the data collected and create ideas and analyses evident in the course of the study. Ellipsis was used to show that there were unnecessary data shared by the participants that were deleted during the data analysis. This was done to show the clearer presentation of the narratives of the participants. Other documents such as awards, and photos gathered from the participants confirmed the reliable description of what was observed.

Data Analysis

In a qualitative research, the data are often in the form of words such as interviews, archival writings, and observations. Qualitative analysis requires researchers to look at words, phrases and observe behaviors that will lead to some sort of meaningful discovery or conclusion (Schreiberan & Asner-Self, 2011). The information obtained from the interview of the research participants of the study were analyzed using qualitative interview analysis and narrative data analysis. Qualitative interview analysis provided ways of discerning, examining, comparing and contrasting, and interpreting meaningful patterns or themes collected during the course of qualitative research. The transcription would be the basis of the researchers to know where the participants learned or gained their experiences and knowledge about child-rearing. It will help them establish or assess the experiences of the participants which are helpful tools for the better result of the study. To assure validity of the study, data triangulation was done using the focus interview and the actual observation. Triangulation was done after the data was obtained from the participants. Triangulation is used by qualitative researchers to check and establish validity in their studies by analyzing a research question from multiple perspectives (Guion, Diehl & McDonald, 2011, para.1). Data triangulation, which entails gathering data through several sampling strategies, so that slices of data at different times and social situations, as well as on a variety of people, are gathered (Denzin, 1970).

Ethical Considerations

This research underwent the ethical review by the College of Education Ethics Committee before it was conducted. The instruments were carefully evaluated to avoid making the participants experience physical and mental discomfort, harm, or danger while participating in the study. The participants were informed of all aspects of the study. Participants were also informed about their right to refuse to participate in the study or to withdraw from participating at any time. Furthermore, an informed consent was also secured and the participants were given consent forms wherein objectives of the study were explained to them. Participants then agreed to commit themselves. They were likewise given information about how their data will be used, what will be done with the photos, audio and video recordings. The information obtained from the participants during the course of the study were considered confidential. Only the researcher and members of the panel had the access to the collected data. The researcher assured the participants that the valuable and sensitive information they shared with the researcher were protected. They were given pseudo names to protect their identity.

Results and Discussion

This section gives description and explanation of the results. It has two main parts: (1) The Narrative: A Special Kind of Love for a Child with Down syndrome, (2) Life's Surprises (Experiences), (3) A Victor's Triumph (Successes), (4) Passionately Passionate (Challenges), (5) Parents: Cradle of Persistent Inspiration (Aspects and Features of Parenting)and; (6) Defying Disability (Lessons Learned)

Part One, The Narrative: A Special Kind of Love for a Child with Down syndrome, includes the description of the family and the story of their child-rearing experiences of parents in raising their child with Down syndrome.

Part Two, Life's Surprises (Experiences), includes the parent's child-rearing experiences in relation to the disability of their child;

Part Three, A Victor's Triumph (Successes), contains the achievements that the parents have had with regards their efforts in raising their child.

Part Four, Passionately Passionate (Challenges), discusses the problems and struggles that parents encountered in raising their child.

Part Five, Parents: Cradle of Persistent Inspiration (Aspects and Features of Parenting), described how parents raised their child to reach her full potential.

Part Six, Defying Disability (Lessons Learned), enumerates the lessons that the parents learned that they would love to share to other parents having children with Down syndrome.

The Narrative: A Special Kind of Love for a Child with Down Syndrome tidal wave coming for the family, threatening to make them lose their balance, to fall, to give up; but they do not, they never do.

Just like the story of a couple who had embraced and nurtured a child which once struck fear into their souls.

Mr. and Mrs. Santos live in Jaro, Iloilo City. The father, Mr. Santos, Jr., 62 is a college graduate and now a retired policeman who receives a monthly pension worth forty-five thousand pesos. The mother, Mrs. Santos, 65, a college graduate and also a retired policewoman who also receives a monthly pension worth forty thousand pesos. They met when they were in the service and fell in love with each other. They got married and they were blessed with three children, Grace, 30 years old, is the youngest and only daughter in the family who happened to have Down syndrome, with two elder brothers.

Mr. and Mrs. Santos had never thought about the unforeseen changes that would happen in their lives the moment their third child was born. Everything was perfect and happy as they waited for the new life to come out. All of them were so excited to meet that little girl whom they had been waiting to see. It seemed like a perfect moment for all of them.

But that happiness faded as the doctor told them that their daughter had Down syndrome. It was not easy to accept the truth neither watch that little angel struggle in pain caused by an inborn sickness.

"Pagkuwan sang doktor, nakita nia dayon nga may DS...Siyempre masakit eh, daw, basta kalaw-ay. Dugay-dugay man kag naanuhan kag na kwan ko man nga ti nga-a haw kung may deperensya? buligan na lang," Mrs. Santos said.

(When I gave birth to her, the Doctor realized that she had Down syndrome. It was painful for me...I cannot explain how I felt! It took some time for me before I could reflect and tell myself so what if she has a disability? I'd rather help her.)

It took some time for them to accept and realize that their child has Down syndrome. They experienced denial within the first few days after they learned about their child's exceptionality. They grieved the loss of the ideal child they dreamed of. As parents, their child having Down syndrome required them both to cope and to face the challenges of adjusting with the condition of their youngest child.

Mrs. Santos shared, "Nag ano nalang kami, buligan ta gid nga maka ano sia

(overcome iya disability)."

(We had agreed that it's our responsibility and we pledged to help our baby overcome her disability.)

Mr. Santos added, *"Gina ano na bala, kami ya wala, daw wala man namon gin tago nga may deperensya si Grace. Ginapalangga gid sia, ginbaton gid sia dayon."*

(I have accepted our fate and we never feel ashamed of having a baby with Down syndrome. We never hid the fact that Grace was different. We loved and accepted her unconditionally.)

Mr. and Mrs. Santos asked for help and support from their families and friends to face these challenges in raising their child with Down syndrome. As their child grew up, they noticed that she was talented. This is proof that not all kids with Down syndrome are hopeless. Knowing that capability of their child, they grabbed the opportunity and did their best to develop their child's future. Both parents had stable jobs when Grace was born, they were able to support all her needs, providing her with material things she needed, at the same time enrolling her in different schools and special classes. Apart from the pension that Grace's parents receive monthly, they also own a sari-sari store.

With early intervention, special education programs, inclusion, better social acceptance, support groups and medical care, Grace's future seems secured.

Mrs. Santos said, *"Tapos ako gid ang mag atipan/tudlo sa iya kung sa bagay sang may buot na sia indi na gid man mabudlay nga i-train kay trainable gid sia iya. Ti kay pareho sina gina tudluan namon ina kung paano magpaligo kag magilis... Gaeskwela pagid na si Grace kay Dr. Raquel. Kon morning ara sia sa SPED pagkahapon didto naman cia kay doktora ga eskwela. Tapos naga ballet pa sia, daw gin develop gid namon na bala. May speech therapy pa na sia... 11 years old sia kag mag swim, primero nahadlok na sia sa tubig pero sang nakabalo na sia nagpaninguha gid na sia, "*

(So I really took good care and trained her to take a bath and dress up since she really is trainable. Grace goes to two schools at SPED and with her doctor, Dr. Raquel to develop her skills and talents. She also dances ballet and we really tried to let her experience many things. She likewise has speech therapy. She learned how to swim when she was eleven. At first she was afraid of the water but eventually liked it.)

As stated in the journal of Crowns (2012), in helping children and young people to develop and achieve their potential, effective healthcare, good parenting skills, everyday family activities, early intervention in their first years of life to support development, good education at primary school, secondary school and in further education, sports, recreation and community activities and vocational

training and work are needed. Turnbull & Turnbull (1990) also claim that, parents who have children with disabilities often feel that they must help teach their children, make sure their children get services, and work toward their children's inclusion into the school and community. With these support provided by the parents to their child with Down syndrome, she was able to receive different awards and recognitions such as Outstanding Performance in Aquatics during the 2013 Asia – Pacific Special Olympics Inaugural Games at New Castle, New South Wales, Australia; Silver Medalist in Aquatic Event (100m breaststroke) during the 3rd ASEAN Games at Rizal Commercial Complex, Manila, Philippines, 2005; Silver Medalist in Swimming Competition during ASEAN Paraplegic Games, 2005 and recently won Four Gold Medals in Rhythmic Gymnastics specifically in ball, ribbon, hoola-hoop and rope category last June 2015 at Los Angeles, California during the Special Olympics. She also received recognitions from her school for her exemplary performance. The mother shared that their child had helped them morally, emotionally and financially. She makes them happy in her simple ways such as learning the skills they taught her like caring for herself, performing onstage in her ballet dance and competing in local, national and international competitions.

Mrs. Santos shared, *“Ang nabulig ya siguro ti nga nakabalo na sia mag care sa kaugalingon ya eh. Du mga 10 y.o na si Grace sia na na tanan sa kaugalingon nia, indi na kinahanglan nga may mapapaligo sa iya. Nagtinguha gid sia nga mabuligan ang kaugalingon nia...”*

(Our work reduced when she learned to take good care of herself. She really tries her best to be self-sufficient.)

Mr. Santos also added, *“Isa pa gid pareho sina maka lakat-lakat kami sa abroad kay ti indi na kami mabudlayan magkwa sang mga visa, hapos na lang bala. May ara man nga sila nalang naga hikot sa Manila naga abot nalang sa amon ang amon mga papeles nga malakat na. Amo gid na ang nabulig gid ni Grace sa amon.”*

(Going abroad was made easy for us especially because Grace is handicapped. Getting visa and passport with her was as easy as these being handed to us because of Grace.)

As time passed, they began to look at Grace's birth very differently. Far from the grief and despair of her condition, they felt joy and pride. Even though their child had done her best in her performances in different fields that she was trained into, the parents cannot avoid worrying about how will she fit into the family as well as to fit in to society especially when they are gone.

Mrs. Santos said, "Ginakabalak-an man namon ang iya palaabuton.

(We are concerned with what her future will be.)

Mr. Santos also shared, *“Siyempre ginakabalak-an namon na sa iya ang indi na kami mag atinder, ang ano sa iya bali eh, kay siyempre kung ang mga utod nia daw lain gid ya kag ang ginikanan daw maluoy ka gid kung manumdon ka gid nga indi sia kasarangan sang iya pangabuhì kay wala sia trabaho tapos may ibilin ka man sa iya daw indi gid sia kasarangan nga sia lang.”*

(We are concerned on how she can take good care of herself. Her siblings also love her but it is different when it is us, the parents. Also, we care a lot what she will do in the future because she cannot have a job. And even if you leave something for her she cannot really do anything about it because she can hardly take care of herself.)

The parents thought that the future of their child looks like the frightening unknown. As Featherstone (1980, p.136) claims, the common admonition is to "take things one day at a time" particularly appropriate not only because there are more than enough responsibilities for the family in the present but also because the future is so uncertain.

As their other children grow and mature, the parents continue to provide guidance and let them know their responsibilities not just for their special sibling but to their family. As their child-rearing goes on, the parents were able to rear a positively parented child with Down syndrome who exhibited higher levels of independence, language skills, emotional expression and social interaction with adults and peers (Dyches, Smith, Korth, & Mandleco, 2012). Both parents have tried to help their child to make good choices and offer guidance and discipline. They also respect their child's self-will but balances it with disciplined conformity. As Morgenegg (2013) claims, positive parented children often develop into happy, self-confident, capable, and successful adults. Smith (2012) also added that in households where positive parenting is applied, the symptoms and severity of the child's disability are more likely to decrease over time and the greater the child's development.

The best part of their story was when the parents had learned that acceptance, deeper understanding of their child's condition and unconditional love are the answers.

Mrs. Santos shared, *“confident ka nga kabalo sia tapos happy ka man kay parte ka man kung ano sia subong.”*

(Acceptance is the key. Once you accept her as she is then you will be happy with the simple tasks she can do because you are a part of what she has become.)

Despite of the initial heartache, Mr. and Mrs. Santos were able to accept the fact that Grace had given them happiness that any parents would wish to feel it too. Grace made her parents proud of her and she is a living proof that her parents were responsible parents.

Mr. Santos also added, *“Ang mahambal ko lang sa ila nga dapat gid nila labaan ang ila pag-intindi sang bata nila tapos palanggaon*

gid sila, e-guide sang maayo kag tudluan sa maayo. Dapat batunon gid nila nga mo gid na ila bata,”

(All I can say is that they should have deeper and fuller understanding of their child, love them unconditionally and guide them well. They should accept their child as she is.)

Indeed, deeper and fuller understanding, unconditional love and proper guidance had help Mr. and Mrs. Santos in raising their child with Down syndrome and developing her into her full potential.

Their love for their children compels them to stand strong against the tide crashing against them: the stares, the school system, the medical billing, the ignorance from other people, or the lack of support. Although they stand strong, they get tired, sometimes they were barely keeping their feet planted and they fear the tide will finally defeat them and wash them away. So, they reach out and hold each others hand. Because Mr. and Mrs. Santos knew that together they are stronger, and because they need someone to stand with them.

The researcher wanted to recognize the hard things about parenting a child with special needs, and hope that someday people will understand what it is like to walk in the shoes of Mr. and Mrs. Santos.

Based on the answers of the parents and the peripheral participant in the interview together with the actual observations, here follow the formulated themes for the study.

Theme 1: Life's Surprises (Experiences)

Oftentimes when people ask Mr. and Mrs. Santos to describe the experience of raising a child with Down syndrome, to try to help other people who have not shared that unique experience to understand it, and to imagine how it would feel. They shared it with no hesitations and doubts.

Responding to Reality. Both the mother and father communicated that they were at first hurt knowing that their daughter has the syndrome.

It is painful beyond belief to be told that their precious new baby had Down syndrome. Instead of feeling that special sense of joy, they felt as if their world had been turned upside down. At first, they did not care whether their baby is a girl or a boy, they just wanted a healthy baby. But it seemed that the baby they expected did not arrive.

Mrs. Santos shared, "*Pagkuwan sang doktor, nakita nia dayon nga may DS...Siyempre masakit eh, daw, basta kalaw-ay.*

(When the doctor in the hospital saw the baby they right away knew that the child has a Down Syndrome not until it came out. It was painful for me...I cannot explain how I felt!)

Certain studies have presented various results as to how people react to specific events that build their way to know beyond their knowledge. In this study, the parents concerned were interviewed about their experiences in rearing their child with Down syndrome. Both the mother and father communicated that they were at first hurt knowing that their daughter has the syndrome. Perlin & Schooler's (1987) study about passive appraisal had shown consistency with regards to the statements made by the parents during the interview conducted for this study.

Seeking Options. The parents' eagerness to provide the support needed by their child and early intervention played a great role in developing the child with Down syndrome.

The pang of the truth may have stayed with them for a while but the strong bond between have made them support their daughter to the best that they can had overpowered that pain that they have had at first. Mr. and Mrs. Santos continued to seek help and assistance for their baby as she grew.

Mrs. Santos said. "*Dugay-dugay man kag naanuhan kag na kwan ko man nga ti nga-a haw kung may deperensya? buligan na lang. Nag ano nalang kami, buligan ta gid nga ma-overcome nia ang iya disability*

(It took some time for me to accept the fact that she'll never be like those other kids we see. I will just help her. It's our responsibility and we pledged to give our lives to help our baby overcome her disability.)

The daily care of their child with Down syndrome was different from the care they had provided to their other children. Just as they experienced stress as parents of a child with Down syndrome, their other children may found it stressful also to be the siblings of a child with disabilities. But the strongest factor in their adjustment was the reaction of the parents. They followed their parents' lead in interacting with their sister. The siblings dealt better with Grace because they had the information given to them by the parents appropriate to their age level and expanded it as they grew.

Mr. Santos shared, "*Ginapalangga gd sia, ginbaton gid sia dayon...Kung sa iya nga mga magulang wala man sang problema, basta kay ginapalabi gid namon si Grace kay tatal may bu-ot naman ang duwa, mas ginatendir gid namon sia... Ginapaintindi man namon sa ila nga mas kinahanglan ya ni Grace ang bulig namon kay amo na iya sitwasyon.*

(We accepted and loved her unconditionally. As for her siblings, they accepted Grace whole heartedly as well. Due to the sickness that Grace has, we dedicated more of our time in taking good care of her. We are very happy that her older siblings did not mind us giving more time to their little sister. We did our best to make them understand that their sister needs more attention and care and we are glad that they were positive about it.)

Because their baby differs from typical children in some ways, her daily care required special knowledge and effort. They started with routine activities such as eating, bathing, diapering, and dressing. These tailored activities had helped them to enhance Grace's development simply by being aware of her developmental needs as they went through each day.

Mrs. Santos relates, *ginakabalak-an man namon ang iya palaabuton. Amo na gani nga gina preparar namon sia nga makabalo gid sia sa kaugalingon ia nga mag care tapos gina train namon sia nga sia lang makabalo kay sa pila ka adlaw nga ma mapatay kmi daw mabal-an na gid nia kung paano atipanon ang kaugalingon nia.*

(We are concerned with what her future will be. That is why we are preparing her now to learn how to take care of herself. We are also training her to take care of herself even when we are gone someday.)

The mother's statement about accepting the disability of their child agrees with the research done by Cunningham (2006) which talks about the family's ability to cope in the face of life stresses. Struggling with the thought of confusion on the situation of their daughter has been evident to both of parents. Concerns about their daughter's welfare, for now and the future have been openly shared by the parents. A lot of questions pertaining to "how" are directly contributing to the ambiguity of Grace's future. They believed that they Grace can still be helped, so they seek advice for early intervention. As the word says, intervening early in a child's life to encourage growth and development. Grace's Early Intervention Program was tailored to her specific needs and her family's.

Mrs. Santos shared, *"gaeskwela pagid na si Grace kay Dr. Raquel. Kon morning ara sia sa SPED pagkahapon didto naman cia kay doktora ga eskwela. Tapos naga ballet pa sia, daw gin develop gid namon na bala. May speech therapy pa na sia."*

(Grace goes to two schools at SPED and with her doctor, Dr. Raquel. She joined ballet too. And she also has speech therapy.)

Surviving the Maze. Parents' love, care, support, understanding, patience, and encouragement to their child made her overcome her disability.

From the day of Grace's birth, both her mother and father has done their very best to sustain all her needs. Teaching her to live a normal life has been her parent's main goal ever since they have come to know of her condition. Obstacles intervening her improvements have been thoroughly overcome by Grace with the unrelenting guidance of her loving parents. "Taking things one day at a time," could be a specific and note-worthy standing principle of the parents that went through tough trials in life. Grace's parents have faced various challenges as they were rearing their child. Health condition, self-help skills, financial, trainings, and attitude problems have been some of the pieces of the puzzle that they are trying to complete.

All of the parents' sacrifice out of their love for Grace, has been reciprocated by their child through her simple ways such as learning the skills they taught her like caring herself, performing on stage, in her ballet dance and competing in local, national and international competitions. Rigid training and tender care for their delicate child have been the parents' greatest armor as they face every day's battle against negativity.

Theme 2: A Victor's Triumph (Successes)

Every individual has been blessed with specific victories in life. Each one has the champion of his/her own tournaments in his/her journey.

Who is Grace and what makes her different?

I am Ready! Guided instructions in doing self-help activities and practice influenced the child's progress.

She is special in a way that she becomes more than other people could ever think that she could. Considering her condition, Grace had fought bravely in the fight of her life. She has rendered her full modesty of being the best version of herself. Grace had learned guided instruction in doing self-help activities. Her progress was also influenced by practice. During the actual observation, Grace showed independently how to prepare and serve her food, to feed herself, to bathe, and to do her daily exercise routines. Both her mother and father are worthy to be praised for her admirable deeds.

Mrs. Santos added, *"ang nabulig ya siguro ti nga nakabalo na sia mag atipan sa kaugalingon ya eh. Du mga 10 years old na si Grace sia na na tanan sa kaugalingon nia, indi na kinahanglan nga may mapapaligo sa iya. Nagtinguha gid sia nga mabuligan ang kaugalingon nia..."*

(She helped us a lot when she learned to take good care of herself. She really tries her best to be self-sufficient.)

The statements of the parents and teacher simply show that Grace had grown beyond the what they had expected of her. During the actual observation, it was explicitly studied how Grace proved her capabilities when it comes to her self-help skills.

Actions Speak. The acquired and developed skills of the child with Down syndrome helped her become successful.

Details pertaining to her struggles and success in living her wonderful life is an asset which Grace and her family will forever treasure. Through years of training and perseverance, Grace had proven that there could be no unattainable things in life, only those that had been given up. Studies such as one of those conducted by Cunningham (2016) which indicates that those parents who go out and look information, services and support do obtain great benefit from support and services. The children of parents who make full use of support networks also have children with more self-sufficiency, presumably because they benefit from more social contact and social independence when they are involved in social and group activities. Also, the study of Alava (2015) in which she claims that parents' support varied from giving time and attention, providing every need of their child at home and at school, teaching their child basic skills, making the decision to place their child in special education, enrolling in other talent-based classes, father's involvement, and financial provision. Parents also give extra time and attention to their child with disability than to their other child/children without disability. Understanding the unique characteristics of their child and administering tons of patience also led their child with intellectual disability to feel accepted. These studies cited have been a brick wall that holds the idea of how Grace has come to reach her vivid state of victory over her disability. All the way, Grace's family has shown a positive contact and relations with her as she grow up. Trainings have also been a great part to the nourishment of her talents and capabilities.

With these supports provided by the parents to their child with Down syndrome, she was able to receive different awards and recognitions such as Outstanding Performance in Aquatics during the 2013 Asia – Pacific Special Olympics Inaugural Games at New Castle, New South Wales, Australia; Silver Medalist in Aquatic Event (100m breaststroke) during the 3rd ASEAN Games at Rizal Commercial Complex, Manila, Philippines, 2005; Silver Medalist in Swimming Competition during ASEAN Paraplegic Games, 2005 and recently won as Gold Medalist in Rhythmic Gymnastics last June 2015 at San Francisco, California during the Special Olympics. She also received recognitions from her school for her exemplary performance. The mother shared that their child had helped them morally, emotionally and financially since because of these games that Grace joined, both parents were also able to travel with her and to witness her success.

Mirror of My Victory. Trainings have also served a great part in the nourishment of the child's talents and capabilities. The exceptional performance that the child gave her parents the satisfaction that they had raised their child well.

Grace did not just make achievements in sports but she was also performing well in school and in her trainings. In 1996, she won as 2nd Runner-up in McDonald's MAKABATA Awards held in Manila, Philippines. She had accomplished the Therapeutic Massage Training offered by Breaking Barriers for Children and Young Adults with Disabilities (BBCY), Iloilo City last 2009. She was also awarded by the BBCY Training and Development Center (TDC) as the MOST VERSATILE YAWD (Young Adults with Disabilities) and for her participation in the development trainings and vocational courses they offered last 2011. She was also awarded as Most Well - Groomed and Neat and Clean in SPED – ISEC (Integrated School for Exceptional Children), Iloilo City, last school year 2011 – 2012, Dancer of the Year last 2010. One of her greatest victories was her completion of her Vocational Training Program in Balay-Dalangpan last School Year 2013 – 2014. Grace had made her parents happy in her simple ways such as learning the skills they taught her like caring for herself, performing ballet onstage and competing in local, national and international competitions. Seeing these awards, Grace 's parents were proud of what their child had become after the long struggles of training, support, patience, and understanding.

Theme 3: Passionately Passionate (Challenges)

"I cannot explain how I felt! It was much later that I realized it does not matter if she is different...I will just help her... All of us were one on deciding that we will help my baby overcome the disability."- Grace's mother.

Facing the Dark Side. Both parents were worried about their child's future knowing that she has Down syndrome.

Parents will never give up on their children. That has been proven by Grace's parents throughout the years of being there for their daughter every step of the way. Both parents were scared, worried and hurt they felt knowing that child has Down syndrome. Somehow they accepted it and have resolved not to be ashamed of the condition of their child. Grace's parents have reflected great sense of family as they have shown extra care to her.

Mr. Santos shared, "*siyempre ginakabalak-an namon na sa iya ang indi na kami mag atinder, ang ano sa iya bali eh, kay siyempre kung ang mga utod nia daw lain gid ya kag ang ginikanan daw maluoy ka gid kung manumdon ka gid nga indi sia kasarangan sang iya pangabuh kay wala sia trabaho tapos may ibilin ka man sa iya daw indi gid sia kasarangan nga sia lang."*

(We are concerned on how she can take good care of herself. Her siblings also love her but it is different when it is us, the parents. Also, we care a lot what she will do in the future because she does not have a job. And even if we leave something for her, she cannot really do anything about it because she can hardly take care of herself.)

The statement of the father was consistent with the study of Featherstone (1980), wherein he claims that the future of an individual with exceptionality looks like the frightening unknown. He added that the common admonition is to "take things one day at a time" particularly appropriate not only because there are more than enough responsibilities for the family in the present but also because the future is so uncertain.

“It was total acceptance for me when I saw how others feel ashamed of having a Down baby. For us, we did not hide the fact that Grace was different.” – Grace’s father.

The statement of the father clearly shows how blessed Grace is, to face the challenge of life with such passionate family with her side, guiding her all along as she grows in line with her inspiring life.

Financial Distress. Over expenditure on trainings of the child was one of the challenges that the parents faced, however her exposure with those trainings molded her as a person.

Both parents have shared their main concerns such as training Grace to be prepared for her future and how Grace will take good care of herself when they are gone. Mr. and Mrs. Santos never gave up on what they wanted for their child. Grace’s brother even remarked, “...they exposed her to the world which really molded Grace as a person.” This part of her brother’s statement is very much true to the fact that even though there were challenges faced by the family, considering the situation, Grace and her family has stood firmly and have adjusted their sails to the waves brought about the sea of life that they are eagerly living to promote their unending love for each other as a family.

Pertaining to their story of inspiration agrees with the study of Bashir, Kurshid and Qadri (2014) which concluded that majority of parents suffered due to over expenditure on treatment of the child due to which other expenses did not meet and affect overall family. Parents have been affected in different ways but majority of them stated that mental stress invites many problems in family as their whole mind and time revolves around the disabled child. However, Mr. and Mrs. Santos were able to handle those sufferings only to give the best for their children especially to Grace.

Hissy Time. Parents knowledge about their child’s attitude and providing their love, understanding, and patience had helped them to solve their child tantrums problem.

Children with Down syndrome almost always have some degree of intellectual disability. That is, they learn slowly and have difficulty with complex reasoning and judgement. In the case of Grace, there were times that she had her tantrums and attitude problems especially when she wanted to do something but she was forbidden to do so.

Mrs. Santos elaborated, *may time na nga kung indi nia gusto indi mo gid mapilit. Basta ulu-uluhan mo lang indi mo gd sia pagpiliton gid kay kung sigohon gid naga tantrums sia, kag indi nia gusto, maaway lang gid kmi. Talagsa lang man gd sia ga tantrums kay daw indi gid sia kumpormi nga gina tudlu-an mo. Ang gusto niya na pirmi gid sia sa tubang kag sia ma leader. Si Grace na ang mauna, nagasunod lang man sila pero sang may buot na sia naga nagapati na sia nga dapat sa sunod sa likod lang sia para makakita kung ano ang ginahimo sang iban.*

(There are times that she refuses to do all these. You have to be soft spoken and coax her to reduce tantrums. She sometimes does not want to be taught. She wants to be in front of the line and be the leader often. Now that she is older she is comfortable to stay at the back of the line.)

As Grace grew, up her parents had learned to get to know her especially in times that she needed the most their understanding, patience and love.

Theme 4: Parents: Cradle of Persistent Inspiration(Aspects and Features of Parenting)

A parent fears the fact that something could be wrong with his/her child as he/she is growing up, how much more knowing that indeed, there is really something that is beyond nourishing her is an epitome of motivational parenting that would not only inspire other people but more.

Motivational Parenting. The moral support provided by the parents played a big role in motivating their child with Down syndrome during her performances.

Grace's condition was as challenging as the life she was about to live, when she was born. Grace’s parents did their very best to nurture and develop her skills to its full potential. It provided her needs, not only financially but also morally. Whenever Grace was expected to perform in front of the large crowd, her parents are always there to boost her self-confidence.

Mrs. Santos said that, *"ang kwan lang siguro, ang moral support... Ti dapat tiyaga-an mu gid sia pero kung teachers ang gatudlo sa iya ga cooperate gid na sia."*

(Moral support is crucial. You have to diligently and patiently mentor her as well as be cooperative in her school. With her teachers, Grace really cooperates.)

They had given the support that Grace needed the most to believe in herself especially during her competitions.

Mrs. Santos shared, *ara ka gid kung maghampang sia, ara ka gid nga maghambal "Ga nami-on mo gid para mag daog ka". Pareho man kung mag saot sia. Gina dugangan mo boost ang confidence nia para madumduman nia nga ari kami para sa iya. Ga memorize man ako, dapat gid for example sa ballet ya. Ginapamemorize ako na sang teacher para ma memorize ang practice nia para pag abot sa balay review kami. Nag effort man ko ka tudlo-tudlo sa iya eh. Kung indi maayo ang iya mood, ulu-ulohan mo anay kag pabay-an*

lang anay tapos kung mag nami na ang mood ya dira na kami mapalapit sa iya.

(You should be present when she plays, advice her to do well to win. It is the same when she dances; you have to boost her confidence so she will realize we're there for her. I also memorize her ballet steps to be prepared to coach her when we reach home. I put in effort to teach her. You really need to be patient with her all the time. You cannot force her or she will go into tantrums.)

Disciplinary Measures Over Child's Condition. Authoritative or positive kind of parenting fostered by the parents had made their child's self-will balanced with disciplined conformity.

Mr. and Mrs. Santos had given their full understanding, patience and love to their child. Moreover, during the actual observation it was also observed that both parents had instilled discipline in their household. These were observed everyday especially in Grace's daily routine (see Appendix G). Both parents ensured that Grace performed each routine that she needed. In the morning at around 6:30 a.m. or 7:00 a.m. Anya did her daily exercise for 30 minutes. She observed wearing proper attire in doing her activities. If she was going outside the house, sexy clothes are not allowed. In eating her meal, the parents checked if Grace eats healthy food. They do not allow Grace to eat junk foods. Grace also demonstrates modesty and courteousness in answering the phone. Even with the presence of discipline, the parents tried to explain to Grace the do's and don'ts of her actions.

In these instances,, Mr. and Mrs. Santos had foster an authoritative or positive kind of parenting wherein they balance between helping children make good choices and offering guidance and discipline ;and they respect the child's self-will but balances it with disciplined conformity. Positive parenting requires frequent eye contact, use of positive affirmations rather than criticism, seeking to understand the child, and responding immediately. As a result of this style, children often develop into happy, self-confident, capable, and successful adults (Morgenegg, 2013).

Moreover, the parenting style of the parents was aligned with the studies of Dyches, Smith, Korth, and Mandleco (2012) wherein they found out that positively parented children in their studies exhibited higher levels of independence, language skills, emotional expression and social interaction with adults and peers. They also demonstrated improved temperament.

All these are implications that Grace's parents never failed to rear her in a way that she has grown up normally and that she was able to enjoy and explore life like any other normal children.

Theme 5: Defying Disability (Lessons Learned)

What does it take to finally realize the value of success in rearing your child? Is it about their high grades? Their extra-curricular activity? Their achievements? In what way should we see it through the eyes of our present time? How would we decipher the theories behind every victory that's presented before us? Grace's story of her endeavors and triumph has been an avenue of guidance for her fellows and by fellows, those students who are also like her, special and talented. In her every year, her parents unending support has been her stepping stones to where she is at now.

Love and Acceptance. Mixed feelings toward the child's condition as she grew, but the feeling of love and acceptance still prevailed.

The birth of Grace came as a shock to her parents.

"I cannot explain how I felt! It was much later that I realized it does not matter if she is different... I will just help her... All of us were one on deciding that we will help my baby overcome the disability." – Grace's mother.

"It was total acceptance for me when I saw how others feel ashamed of having a Down baby. For us, we did not hide the fact that Grace was different." – Grace father.

These above statements, clearly shows that Grace is one of those children who are suffering the said disability, but has overcome it through her parents. "We live everyday knowing that we are bound to face various challenges that could either make or break us."

Discipline with a Heart. Discipline needs to be applied consistently in teaching the child with Down syndrome.

Disciplining a child with a disability might be difficult to do. Parents usually felt sorry for their child having this kind of disability. They might not be sure if their child understands what is expected of her. As to how Mr. and Mrs. Santos raised their children, discipline was possible especially if applied to their child with Down syndrome. Discipline needs to be applied consistently in teaching the child safe and acceptable manner as observed in the 5-day observation.

The result of the study which shows the motivational parenting that was exhibited by Grace's parents, proves that in any way parents are always responsible for their children regardless their condition. Grace's parents presented great capacities in rearing her and giving them the best of their parenthood.

This eagerly materializes the fact in which Grace is indeed fortunate to have a family like that. Her story of struggle and victory is an inspiration that could also help other families with children possessing the same disability.

Conclusion

Based on the results of the study, the following are therefore recommended: (1) Parents, SPED teachers, and SPED professionals may work together to provide opportunities for children with Down syndrome to develop their abilities and strengths, providing them the help and supports that can help them live independently. (2) Parents of children with Down syndrome can take an active part in advocating for their child's needs. They can provide the needed support of their child to help them reach their optimum potential. Parents can support their child with Down syndrome by being the sources of love, care, support, understanding, patience, and encouragement. Parents can help their child with Down syndrome feel accepted by providing them a loving home and community. Parents can reinforce the instruction that their child receives in school by teaching their child basic skills such as self-help skills and functional skills. Parents can likewise subject their child with Down syndrome to early intervention and talent-based classes. Furthermore, parents can aspire to provide a supportive home and opportunities for school and community involvement. (3) Teachers may employ various effective strategies that will teach necessary skills to persons with Down syndrome. Education of persons with Down syndrome could focus on the development of adaptive behavior composing the three important skills: conceptual, social, and practical skills. They can use practical application of skills taught in school to help persons with Down syndrome manage their day-to-day living with ease. They can use extra time and follow-up lesson to keep up and enhance their pupils' skills. Strategies of teachers in teaching conceptual skills could include training in communication skills to enable interaction among persons with intellectual disabilities and with persons without disabilities which could also help them develop their receptive and expressive language. Teachers can help persons with Down syndrome develop their social skills through involvement in various local, national, and international competitions. They may use strategies in teaching basic practical skills that focus on learning self-help skills like eating skills, dressing skills, and personal hygiene. Teachers could also use strategies in enhancing fine motor skills like developing skills in cooking, baking, and arts and crafts. Through the various strategies that teachers use, persons with Down syndrome can achieve their fullest potential, and thus eventually become successful. (4) The local community may include persons with Down syndrome in various community programs and activities. Involvement in the community will help eliminate the stigma that they are useless members of the community and that they have nothing to contribute to the community. (5) Parents, SPED teachers and SPED professionals may work together to organize parenting sessions to parents having children with Down syndrome to make them more aware of the practices and strategies in developing their children into their fullest potential and for them to know the services that they can available to help their children. (6) Local Government Units (LGU's) and Department of Education (DepEd) should strengthen their assistance program in giving services and supports for children with Down syndrome. These agencies may work hand-in-hand in providing funded trainings and assistance to children with Down syndrome and their families. (7) Lastly, more studies may be conducted about the child-rearing stories of parents having children with Down syndrome to make more bases in rearing children with this kind of disability especially to families with different economic status. In this way, other parent can also learn to develop and raise their children to their fullest potential and could live independently.

References

- Alava, S., 2015. A Glitter of hope in the success stories of Ilonggos with intellectual disabilities. Unpublished Thesis: West Visayas State University; College of Education, Iloilo City, 2015.
- Allyson, P., 2014. A comparison of parenting dimensions between mothers of children with Down syndrome and mothers of typically developing children. United States: University Of Alabama, ProQuest, UMI Dissertations Publishing, p. 179 pages.
- Bashir, A., khurshid, S. .& Qadri, F.(2014). Awareness and problems of parents of children with autism spectrum disorders. International Journal of Interdisciplinary Research and Innovations, Vol. 2, Issue 2, pp: (42-48).
- Baumrind D., 1967. Child care practices anteceding three patterns of preschool behaviour. Genetic Psychology Monographs, 75: 43-88.
- Brooks, J. (2011). The process of parenting (8th ed.). Toronto, ON: McGraw-Hill.
- Cambridge Dictionary (2016). Cambridge University Press 2016
- Clandinin, J. & Connelly, M. (2000). Stories of Experience and Narrative Inquiry. Educational Researcher, Vol. 19, No. 5 (Jun. - Jul., 1990), pp. 2-14: American Educational Research
- Coffey, A. & Atkinson, P. (1996). Narrative and stories in making sense of qualitative data: Complementary research strategies (pp.54-82). Thousand Oaks, CA. Sage Publication
- Crotty, M. S. (1998). The foundations of social research: meaning and perspective in the research process. Great Britain: The Cromwell Press.
- Crowns, 2012 journals. Retrieved from <http://www.leicspart.nhs.uk/Library/EarlySupportInfoaboutDS2ndEd2012.pdf>
- Cummings, A. (1976). The orchestration of ESL performance. Working paper, University of British Columbia.

- Cunningham, C. (2016). Issues for families with children with down syndrome. Published study in the Down Syndrome Education International. Manchester, UK. Retrieved on December 5, 2014 from <http://www.downsyndrome.org/information/family/overview/?page=3>
- Denzin, N. K. (1970). *The research act in sociology*. Chicago: Aldine.
- Dyches, T., Smith, T., Korth, B., Roper, R. & Mandleco, B. (2012). Positive parenting of children with developmental disabilities: A meta-analysis: Published study in the Research in Developmental Disabilities, November-December 2012. Retrieved on December 5, 2014 from <https://www.lds.org/church/news/parenting-style-is-key-for-children-with-developmental-disabilities?lang=eng>
- Featherstone, H. (1980). *A difference in the family*. New York: Basic Books.
- Fortier LM, Wanlass RL (1984). Family crisis following the diagnosis of a handicapped child. *Family Relations*, 33: 13-24.
- Guion, L., Diehl, D. & McDonald, D. (2002). Triangulation: establishing the validity of qualitative studies. *Journal of Department of Family, Youth and Community Sciences, Florida Cooperative Extension Service, Institute of Food and Agricultural Sciences, University of Florida*, (FCS6014).
- Hardman, M., Drew, C. & Egan, M.W. (2012). *Human exceptionality: Family, school and community*. Philippines: MG Reprographics.
- Hockenbury HD & Hockenbury ES (1997). *Psychology*. New York: Worth Publishers.
- Hodapp, R., Ly, T., Fidler, D. & Ricci, L. (2009). Less stress, more rewarding: parenting children with down syndrome. *Parenting: Science and Practice*. Nov. 18, 2009. Retrieved on December 8, 2014 from http://www.tandfonline.com/doi/pdf/10.1207/S15327922PARO104_3
- Hoffman M.L. (1994). Discipline and internalization. *Developmental Psychology*, 30: 26-28.
- Jacob, A. & Furgerson, P. Writing interview protocols and conducting interviews: Tips for students new to the field of qualitative research. *The Qualitative Report 2012 Volume 17*, T&L Art. 6, 1-10 <http://www.nova.edu/ssss/QR/QR17/jacob.pdf>
- Judy, P. (2000). *The New Oxford Dictionary of English*. New York: Oxford University Press
- Layton, T. (2004). *Developmental Scale for Children with Down Syndrome*. North Carolina: T and T Communication Services, Inc.
- Mauro, T. (2014) <http://specialchildren.about.com/bio/Terri-Mauro-13624.htm>
- Mercado, M.S., (1991). *Introduction to Special Education*. Unpublished Handouts, University of the Philippines, College of Education.
- Merriam-Webster's Student's Electronic Dictionary. 2015. <http://www.mw.com/dictionary.htm> (March, 2015)
- Morgenegg, R. (2013). Positive Parenting is Key for Child with Developmental Disability. *Research in Developmental Disabilities*. November-December 2012. Retrieved on December 5, 2014, from <https://www.lds.org/church/news/parenting-style-is-key-for-children-with-developmental-disabilities?lang=eng>
- Pando, L. M. (2012). Trisomy 21 (Down Syndrome): Jenna's Story. *The Children's Hospital of Philadelphia*. Retrieved on December 7, 2014 from <http://www.chop.edu/stories/trisomy-21-down-syndrome-jennas-story#.VLzMM0eUco4>
- Peniero L.M. & Gatuslao (2005). "Thoughts, feelings, and experiences of a family having a child with pervasive developmental disorder". Unpublished Thesis; West Visayas State University, College of Education, Iloilo City, 2005.
- Powell & Ogle (1985). *Brothers and sisters- a special part of exceptional families*. Baltimore, MD: Brookes Publishing Company. National Dissemination Center for Children with Disabilities, June 2010. National Down Syndrome Society, 2012
- Schreiberand, J. & Asner-Self, K. (2011). *Educational research, United States of America*: Malloy Lithographers.
- Sears, R.R., Maccoby, E. & Levin, H. (1985). *Patterns of Child-Rearing*. California: Stanford University Press
- Smith, D. (2013). Everything and nothing from essex. Retrieved on October 11, 2014 from <http://www.parents.com/health/down-syndrome/raising-a-child-with-down-syndrome/>
- Spivey, B. (2006). *What is Down syndrome?* Super Duper Publications. Retrieved on December 2015 from www.superduperinc.com
- Trute, B. & Hauch, C. (1998). Building on family strengths: A study of families with positive adjustments to the birth of a developmental disabled child. *Journal of Marital and Family Therapy*, 14, 185-193.
- Turnbull, A.P., Summers, J.A., & Brotherson, M.J. (1984). *Working with families with disabled members: A family systems approach*.



Lawrence: Kansas University Affiliated Facility, University of Kansas.

Turnbull, A.P. & Turnbull H.R. (1990). Families, professionals and exceptionality: a special partnership. United States of America: Merrill Publishing Company.

Turnbull, A. P., Turbiville, V., & Turnbull, H. R. (2000). Evolution of family-professional partnerships: Collective empowerment as the model for the early twenty-first century. In J. R. Shonkoff & S. J. Meisels (Eds.), *Handbook of early childhood intervention* (2nd ed., pp. 630-650). New York: Cambridge University Press.

Turnbull, A.P. & Turnbull H.R. (2001). Families, professionals and exceptionality: collaborating for empowerment, 4th edition. Upper Saddle River, NJ: Merrill/Prentice Hall.

Turnbull, A. P., Turnbull, R. L., Erwin, E. J., & Soodak, L. C. (2005). Families, professionals, and exceptionality (5th ed.). Upper Saddle River, NJ: Prentice Hall.

Wilt, M. (2014). Loving Emily. Syndrome: Parents Sharing. Retrieved on October, 11, 2014 from <http://downsyn.com/joomla/index.php/articles-about-down-syndrome/loving-emily-by-mary-wilt> 2014

Wishart, J., Imrie, K., Gray, R., & Muir, W. 2001. What is Down Syndrome?: Balgreen Road, Edinburgh, published by the Scottish Down's Syndrome Association.

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