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## Exploring the Well-Being of Adolescents with Developmental Disabilities through the Lens of Filipino Families

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#### **ABSTRACT**

Well-being, which encompasses quality of life, life satisfaction, and happiness, is locally understood as 'kaginhawaan' or 'kagalingan'. In special education, the concept of well-being is not clearly defined among families with members who have developmental disabilities. Hence, this multiple case study sought to determine how Filipino families perceive the well-being of adolescents with developmental disabilities (ADDs). Through purposive sampling, seven families and their ADD were selected as participants of this study. Qualitative data was gathered through interviews and field observations. Data analysis involved two levels of analysis that began with a within-case analysis of each family unit. Then, through cross-case synthesis, further thematic analysis was conducted by aggregating findings from each family case. The results revealed nine themes that represent family perceptions on the well-being of their ADD. These perspectives include: (1) being provided lifelong support by the family, (2) learning functional life skills, (3) being productive despite the disability, (4) being independent despite limitations, (5) living with dignity despite the disability, (6) addressing health and safety independently, (7) experiencing belongingness and being included in the community, (8) raising own family beyond limitations of disability, and (9) developing spirituality and trusting in God's provisions despite the challenges of the disability. These were utilized to contextualize the concept of well-being that includes dimensions that Filipino families regard as important for their ADD's lifelong well-being. The study advocates for the provision of special education and creation of individualized transition plans (ITPs) informed by the dimensions of well-being that were identified and prioritized by Filipino families to ensure relevant goal-setting and effective instruction to support the lifelong well-being of ADDs.

**Keywords:** well-being, Filipino family, adolescents with developmental disabilities (ADD)

#### **Background of the Study**

ell-being is described as an "umbrella" term (Upadhyay & Arya, 2015) that is often associated with factors attributed to life satisfaction, happiness, health, flourishing and optimal functioning in all conditions (Estola et al., 2014; McLellan & Steward, 2015; Upadhyay & Arya, 2015). In psychology, for instance, it is related to personal and subjective reports of feelings and emotions, while some economicsoriented studies explored well-being in the light of objectively defined indicators categorized under quality of life (i.e. health status, work-life balance, education and skills, social connections, etc.), material conditions (i.e., income and wealth, jobs and earnings, housing) and resources for future well-being (i.e., natural, economic, human and social capital) (Organisation for Economic Co-operation and Development, 2017). These dimensions are studied to better understand whether life is getting better for people through time. It is evident that disparities regarding the conceptualization of well-being, its components, and its pathways exist (Henderson & Knight, 2012). The debate surrounding what constitutes well-being has enormous implications and influence on practices such as teaching, therapy, parenting, policymaking, etc. since all these endeavors are driven to change individuals for the better and as such requires a vision that embodies what "the better" is (Ryan & Deci, 2001).

In the field of education, well-being is considered as a vital component of a student's ability to function effectively in school and in all life domains (Skrzypiec et al., 2016). For adolescents with developmental disability being in a crucial stage of transition coupled with limitations due to disability render them to become more vulnerable to experience barriers to well-being. Developmental disability poses limitations on independent participation and acceptance in society (Odom et al., 2009, p. 4). The condition is considered developmental due to the presence of delays, disorders, or impairments (usually observed before the age of 22) within domains such as cognitive, communication, social, or motor abilities that manifest during development. In this study, adolescents with developmental disabilities (ADDs) refer to youth aged 11 to 16 years old, diagnosed with the condition of autism spectrum disorder (ASD) and intellectual disability (ID). Individuals

with ASD face challenges in verbal and nonverbal communication, social relatedness, social interaction, and leisure and play activities while those with ID may have "significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills" (American Association on Intellectual and Developmental Disabilities, 2019).

In schools, educational outcomes for these learners have primarily focused on skill-oriented instruction and application in the classroom setting but failed to acknowledge the need to achieve valued post-school outcomes such as personal independence, employment, community participation (Crockett & Hardman, 2010) that contribute to well-being. Findings from the study of Skrzypiec et. al. (2016) suggest that greater attention and priority must be given to improve the well-being and school satisfaction of learners with disabilities while McLellan and Steward (2015) recommend an in-depth exploration of children's wellbeing since studies on adult well-being cannot be generalized and applied to the younger population. The promotion of well-being needs to be given proper attention so that adolescents with developmental disabilities experience positive opportunities that will nurture and enable them to lead happy and fulfilling lives.

Aside from school, the home is also a place to nurture well-being and holistic development. The preservation of life, maintenance of children's health and well-being is considered as common family and parental responsibility (Liamputtong, 2009). Families play a crucial and influential role in promoting the progress, well-being and competence of their children. In the local context, the Filipino family is considered as the fundamental building-block of Philippine society (Jocano, 1995). It is one of the significant sources of security in society, for it provides its members with a "stable reservoir of emotional security and support" (Jocano, 1995, p.3). For Filipino families with members who have disability, child-rearing entails greater parental involvement in initiatives such as sharing expectations with other family members, decision-making, collaborating with professionals, initiating self-education about their child's condition, providing the child's school needs and performing common household tasks

(Rivadelo-Gaw, 2000; Montero, 2009). Other local literature delve deeper into parents' concepts and sentiments about the future (Ramos, 2011), parents' aspirations for their children with special needs (Bernal, 2011), and the wellness of adults with developmental disabilities (Manlangit, 2015). Parentalreported aspirations and sentiments about the future revealed that parents are committed to providing education to their children with disabilities and that they anticipate challenges that their children will encounter in the future such as difficulty obtaining employment, finding love and building a family. Despite these setbacks, parents remain hopeful that the workplace, community and society would accept and bestow respect, understanding, love and compassion to their children (Bernal, 2011; Ramos, 2011).

Overall, available literature on well-being showed the growing interest and importance attributed to this concept. However, well-being studies in the field of special education are scarce, indirect, usually involve only parental reports with limited input from adolescents with disabilities themselves. Due to the subjective nature of perceptions of well-being, the identified research gaps of previous research strengthened the need to study the perception of adolescents with developmental disabilities and their families to reveal themes on well-being that are unique to Filipino families, society and culture. This study makes a valuable contribution to the field of special education and well-being research by identifying dimensions of well-being specific to ADDs. Further, this study would provide a better understanding of the meaning and importance of well-being in our society.

## **Research Objectives**

Well-being is a concept that is not clearly defined in contemporary Filipino families with members who are ADDs. Hence, this study identified and discussed perceptions among families on the well-being of ADDs. Specifically, this qualitative research sought to answer the question: How do families perceive the well-being of their ADDs?

## Methodology

Research Design. A multiple case study was conducted to explore perceptions of seven Filipino

families on the well-being of their ADD. This approach was utilized since it is appropriate for an in-depth investigation of unique perspectives and experiences in the real-world context. (Yin, 2014). A unique feature of the multiple case study design is the application of replication logic. To do so, Yin (2014) explained that "each individual case study consists of a 'whole study', in which convergent evidence is sought regarding the facts and conclusions for the case; each case's conclusions are then considered to be the information needing replication by other individual cases" (p. 59).

Data collection methodologies involved field observations in the different settings where the ADD's life revolves and one-on-one informal interviews with the immediate family members. Data collection began with rapport building to ensure that respondents feel comfortable sharing their thoughts and experience followed by scheduled interviews done in a conversational manner as opposed to structured inquiries. The interview sought to elicit information regarding the ADD's background, his/her usual routine and activities and their perceptions regarding the well-being of their ADD family member. Field observations were conducted to supplement and validate information from interviews.

Qualitative data were subjected to within-case analysis and cross-case synthesis to reveal major themes. In presenting the results, both the individual cases and the multiple case results were the focus of the research report. Across cases, Yin (2014) suggested that the report should explain similar or contrasting results.

Research Participants. The selection process of research participants involved participant screening wherein parents referred by various institutions accomplished a screening sheet that seeks to gather information about their family profile (specifically personal, spouse, ADD and family information), residence, sources of income and the diagnosis, strengths, challenges and other characteristics of their ADD.

Through purposive sampling conducted in four educational institutions in Metro Manila, seven ADD and their 21 family members were selected based on the following criteria: 1) their ADD family member is

11 to 16 years old and he/she has ASD or ID, 2) their residence is located within Metro Manila and, 3) they belong to different socioeconomic statuses (SES). Only families with adolescent members with ASD and ID were chosen as participants of this study because limitations due to their condition pose challenges to their well-being and their family members may offer a unique perspective regarding this concept based on their experiences. These families also represent the low to upper-middle socioeconomic classification based on the family categorization introduced by the Philippine Institute of Development Studies (Albert et al., 2020).

Five out of seven ADD participants were males, while two out of seven were females. Four out of seven were diagnosed with ASD, two out of seven had ID,

and one out of seven had ASD and ID. All the ADD involved in this study attend in and receive education either from a private school, public school or a foundation.

The 21 family members who participated in this research were composed of six father participants (FP), six mother participants (MP), one grandmother participant (GP), one aunt participant (AP), two cousin participants (CP), and three brother participants (BP) and two sister participants (SP). In terms of gender, most of the participants were female (12 out of 21), while the rest were male (9 out of 21). The age range of the participants is between 9 to 66. Table 1 presents the demographic profile of the ADD participants while Table 2 provides a summary of the demographic profile of their family members.

 Table 1

 Demographic Profile of Adolescents with Developmental Disability (ADD)

Family	Adolescent	Gender	Age	Condition	Level of	I	nstitutio	n attend	ed
Code	Code				Communication				
						I-1	I-2	I-3	I-4
1	ADD 1	F	16	DS	Verbal	$\checkmark$			
2	ADD 2	M	15	ASD	Verbal	$\checkmark$		$\checkmark$	
3	ADD 3	M	11	DS	Non-verbal	$\checkmark$			$\checkmark$
4	ADD 4	M	15	ASD	Verbal		$\checkmark$		
5	ADD 5	M	15	ASD	Non-verbal			$\checkmark$	
6	ADD 6	M	13	ASD	Non-verbal			$\checkmark$	
7	ADD 7	F	12	ASD & ID	Verbal			$\checkmark$	

*Note:* On Adolescent Code: ADD – Adolescent with Developmental Disability; On Condition: DS – Down Syndrome; ASD – Autism Spectrum Disorder; On Educational Institution Attended: I-1 – PWD Foundation, I-2 – Private Integrated School, I-3 - Public School 1, I-4 - Public School 2

#### **Instruments**

The researcher-made instruments written in English and translated in Filipino were designed to identify respondents and gather data for this study. These include: 1) a participant screening sheet, 2) an interview protocol for family members, 3) an interview protocol for adolescents with developmental disabilities, and 4) an observation journal. These instruments were reviewed and validated by research panel members. The instruments' format and content were revised to address their comments and include their suggestions. Specifically, the participant screening sheet was made more concise by removing some items and leaving the section on

gender blank instead of having a male or female checklist. Also, a statement was added to the directions in accomplishing the participant screening sheet. It states that participants may opt not to supply information in the demographic profile that they are not comfortable to divulge. Questions in the interview protocols were also simplified (see Appendix 1). These questions served as discussion starters to encourage the participants to share their insights, beliefs and practices in connection with the well-being of their ADD. Approval from the research panel members was sought prior to the use of instruments for data collection.

 Table 2

 Demographic Profile of Family Members

Family Code	Participant Code	Family Role	Gender	Age	Occupation
1	MP 1	Mother	Female	53	Not Employed
	FP 1	Father	Male	47	Fabricator
	CP 1	Cousin	Female	50	Caregiver
2	AP 2	Aunt	Female	47	Not Employed
	MP 2	Mother	Female	45	College IT Professor
	BP 2	Older Broth- er	Male	20	College Student
3	MP 3	Mother	Female	38	Online Seller
	FP 3	Father	Male	35	Delivery Rider
	BP 3	Younger brother	Male	9	Elementary Student
4	GP 4	Grandmother	Female	66	Retired Government Employee
	SP 4	Older Sister	Female	18	Highschool Student
	CP 4	Older Cousin	Female	22	Not Employed
	FP 4	Father	Male	45	Overseas Filipino Worker
5	MP 5	Mother	Female	48	Seamstress
	FP 5	Father	Male	50	Company Driver
	BP 5	Older Broth- er	Male	16	Highschool Student
6	MP 6	Mother	Female	37	Not Employed
	FP 6	Father	Male	56	Government Employee
7	MP 7	Mother	Female	42	Not Employed
	SP 7	Older Sister	Female	23	Call Center Agent
	FP 7	Father	Male	54	Not Employed

#### **Data Collection Procedure**

**Phase 1: Preliminary Phase**. In this phase, the researcher engaged in preparatory tasks before actual data collection. Purposive sampling using a participant screening form was conducted. The screening results were evaluated based on a set of criteria to determine eligible families. Basic information about the family and their ADD (i.e., name, age, educational attainment, occupation, interests, etc.) were gathered using this instrument to create a family profile and participant demographics.

Phase 2: Data Collection Phase. The researcher conducted one-on-one interviews with selected family

members and the ADD. An interview protocol for family members and the ADD was created to serve as a guide during informal interviews.

For each family, data gathering began by establishing rapport with the respondents. Afterwards, the interview with each family member was scheduled. The interview was focused on exploring their perceptions regarding the well-being of their ADD. Interviews were conducted several times whenever the initial interview yielded little response and done in a conversational manner as opposed to structured inquiries. After each interview, the interviewee's key points were summarized and confirmed by the researcher. Field observations were also conducted by the researcher in the family residence,

in school, and in other settings to determine the ADD's daily routine, activities, interests, etc. The observations were used to supplement and validate data gathered from the interviews.

## **Data Analysis**

Data analysis involved two levels of analysis that began with a within-case analysis of each family unit. Afterward, a cross-case synthesis that presents an aggregate analysis of these cases was prepared to present overall findings gathered from the multiple case study.

Within-case analysis. Responses from the one-on-one interview were transcribed and collated per family. Each interview transcript was reviewed, and answers by each respondent that correspond to the interview questions were identified and encoded to a matrix in MS Excel. Similar responses made by the family members were grouped together to determine subthemes for each family unit. This is referred to by

Cresswell (2013) as within-case analysis wherein a detailed description of each case and themes within the case were generated.

Cross-case synthesis. The next step involved the conduct of a cross-case synthesis to further analyze all sub-themes identified in the seven family cases. According to Yin (2014), a cross-case synthesis is a data analysis technique wherein each case is treated as a separate unit of study, then, findings from each case will be aggregated to generate a more reliable conclusion. This second level of analysis was performed by aggregating sub-themes that emerged across families into larger categories. The results revealed major themes that are common across family cases.

#### **Results and Discussion**

This section outlines the findings of this study based on themes that emerged after data analysis. Table 3 presents the results of the cross-case synthesis.

**Table 3**Cross-case synthesis of perceptions of family members on the well-being of their adolescents with developmental disabilities (ADDs)

Major Themes (across families)	Themes per Family	Family	Participant
Being provided lifelong support by the family (7 out of 7 families)	Close Family Ties	1	MP 1, FP 2
	Having a simple and happy life with family	2	MP 2, BP 2
	Living with family for life	3	MP 3, FP 3, BP 3
	Being with a complete supportive and accepting family	4	GP 4, SP 4, CP 4, FP 4, ADD 4, SP 4
	Living in a positive environment		
	Living with family for life	5	MP 5, FP 5, BP 5
	Living in a safe and supportive community	6	FP 6
	Living with family for life	7	SP 7
Learning functional life skills	Having basic literacy, numeracy, functional and vocational skills	1	MP 1, FP 1, CP 1
(7 out of 7 families)	Having a college degree or vocational training	2	AP 2, MP 2, BP 2
	Having basic literacy and communication skills	3	MP 3, FP 3
	Having the best education and extra-curricular training	4	FP 4

	Having basic education, vocational training and communication skills	5	MP 5, FP 5, BP 5		
	Having basic education and livelihood skills	6	MP 6, FP 6		
	Having basic literacy and communication skills	7	MP 7, SP 7, FP 7		
Being productive despite	Getting a job	1	MP 1, FP 1, CP 1		
the disability (5 out of 7 families)	Getting a job	2	AP 2, MP 2		
	Getting a job	3	MP 3, FP 3		
	Getting a job	4	SP 4, CP 4, ADD 4		
	Being productive	6	FP 6		
Being independent	Being independent	1	MP 1		
despite limitations (5 out of 7 families)	Being independent	2	AP 2, MP 2, BP 2		
(3 out of 7 families)	Being independent	3	MP 3, FP 3		
	Being independent	4	GP 4		
	Being independent	7	MP 7, FP 7		
Living with dignity	Having uncertainties about the future	5	MP 5, FP 5		
despite the disability (3 out of 7 families)	Living with dignity	6	MP 6		
,	Uncertainties about the future	7	MP 7, FP 7		
	Living with dignity	7	MP 7		
Addressing health and	Being healthy	1	MP 1		
safety independently (3 out of 7 families)	Being safe and free from harm	1	MP 1		
	Being physically fit and healthy	4	GP 4, FP 4		
	Being healthy	6	MP 6, FP 6		
Experiencing belongingness and being included in the	Being included in the community	1	MP 1, FP 1		
community (3 out of 7 families)	Having increased social awareness and understanding	2	BP 2		
	Having increased social awareness	7	MP 7		
Raising own family be-	Getting married and having a family	1	FP 1, CP 1		
yond limitations of disability (2 out of 7 families)	Getting married and having a family	2	AP 2, MP 2		
Developing spirituality	Having spiritual enrichment	2	AP 2		
and trusting in God's provisions despite challenges of the disability (2 out of 7 families)	Having faith	4	SP 4		

## Perception of family members on the well-being of their adolescents with developmental disabilities (ADD)

Variation in family perceptions was attributed to contextual factors such as socioeconomic status, religion, family characteristics, and the nature of the disability of their family member. Perceptions were also influenced by their personal family experiences such as being a sibling to a person with disability, awareness about the potential of their ADD and their developmental level, awareness of available opportunities, and successful life stories of other persons with disabilities.

Analysis of the findings from this qualitative research revealed nine major themes that represent the wide array of family perceptions on the well-being of ADD generated in this study.

## Being provided lifelong support by the family.

The seven Filipino families regard having positive living conditions with the provision of lifelong family support to their ADD. For two families positive living conditions relate to having close family ties. This means living closer to their relatives because they can provide their ADD with a safe living environment and their family with a steady source of support. For instance, Family 1, being provided lifelong support by and within the family, is related to maintaining close family ties. Respondents MP1 and FP 1 shared that they served as the guardians of their nieces and nephews while they were young and while their mother worked overseas. MP1, noted that growing up with her older cousins was beneficial for ADD 1, saying that "Kaya nga kung minsan malaking bagay din talaga sa kanya may kasama, doon rin siya na-develop." (That is why sometimes I think that growing up with her older cousins was advantageous for her, [since] she was able to develop further.) They served as communication partners and role models promoting ADD 1's speech development and self-care skills, especially during her transition to adolescence. On one occasion, MP 1 shared that she saw her daughter putting a sanitary pad on her underwear. She thought that maybe ADD 1 learned this practice from her older female cousins. Later on, her cousins

moved to the property next door and started living on their own, but their closeness remained. Go (1993), as cited in Tarroja (2010), claimed that Filipino families worked to maintain family ties and extended family support. However, she also noted that most Filipino families' extended nature could be a strength and weakness at the same time. Such is the case for three families who were also living near their relatives but did not receive any support. FP 4 shared:

Ang talagang kailangan lang iyong love. Basically, iyong love is coming from me and my mom. Now, somehow yung family members ko hindi ganoon. Ang consistent lang sa amin, iyong mother ko at ako lang. Ang sinasabi ko lang sa kanya, God will always take care of you. ([At this point] love is what we truly need. Basically, love [for ADD 4] comes from me and my mom. Now, somehow my other family members are not like that. Only my mother and I are consistent [in showing him love]. I keep telling him, God will always take care of you.).

He said that their immediate family members are not supportive, and he does not envision them caring for his son when his mother passes away. When asked to share further he said that it is difficult because he needs someone with a good heart to look after his son.

These findings suggest that contemporary Filipino families still value close family ties. However, in this study living near extended family members does not always result in positive family relationships and an increased level of support.

Two families were led by solo parents. These families considered being with a complete, supportive, and accepting family, living in a positive environment, and having a simple and happy life with their family as fundamental to their ADD's well-being. Their extended family members filled the void left due to parental separation. Variations in the perception and how they view their family situation were evident in these families, signifying that perceptions and beliefs on optimal states of well-being are "shaped and recognized, negotiated by people who interact with each other within a specific socio-cultural milieu" (Castillo,

2019, p. ix).

Findings revealed that fundamental to the wellbeing of ADD is the presence of the family throughout their lifespan. The majority of the families shared that they anticipate that their ADD would live with them for life, and this is supported by grounded theory research on Filipino wellness by Samaco-Zamora and Fernandez (2016) wherein the family unit was identified to be at the core of kaginhawaan (wellness). All sibling participants shared this perception in this study. The overall experience of wellness of an individual is dependent on family conditions such as togetherness, good relations, and provisions of physical and economic necessities. Moreover, Laigo (2007) suggested that siblings did not encounter much difficulty adjusting to the presence of their siblings with ASD and the challenges that came along because they have beliefs and values that enable them to handle each situation with patience and hope.

The seven families in this study identified that their desired conditions of living for their ADD are characterized by having close family ties, having a simple and happy life, being with a complete family, and living in a positive, safe, and supportive community. Overall, in the context of the Filipino family with an ADD member, the presence of the family could be considered as the key to having a life well-lived.

Learning functional life skills. All families in this study have identified learning functional life skills as a theme that contributes to their perceived well-being for their ADD. They strive to provide education for their ADD.

In terms of learning functional life skills, five out of seven families aspire for their ADD to learn to read and write at the very least and to gain functional and vocational skills. For instance, MP 1 and FP 1 still believe that being educated would be beneficial for ADD 1's future and well-being since it will increase her chances of obtaining a career. However, due to the circumstances presented above, they have set lower academic expectations for their daughter. At this point, they would be happy if she learns how to read, write and perform simple mathematical operations.

FP 1 shared, "Sana makapagsulat at makapagbasa siya ng maayos, para kung sakali wala kami kahit pa-paano maipagtanggol man lang niya yung sarili niya." (I hope that she learns to write and read properly so that she could at least defend herself.) When asked to expound further, he said that "Kailangan marunong magbasa, marunong magkwenta, para hindi siya madaya." (She needs to learn reading and simple mathematical computations so that others would not take advantage and deceive her.) As for MP 1, reading, writing and simple math will enable her daughter to become more functional and appropriately respond to warning signs. MP 1 shared, "Oh, bawal mag-punta dyan, eh di mababasa niya, oh bawal pala dito. Kaysa naman wala man lang. Nakasalubong mo na yung mga letra wala man lang, di ba?" (Oh, you are not allowed to do that, at least she can read that she is not allowed there. This is better than not being able to comprehend the letters or words that she encounters, right?)

MP 1 considers literacy and numeracy as essential skills for daily living, while FP 1 believes that it will help ADD 1 protect herself from deceitful people. Moreover, most parents have set lower academic expectations for their ADD and expressed that they would already feel happy if they attained basic literacy skills. Only one family perceived that their ADD has the potential to reach college and complete his degree due to their awareness of his potential and academic skills. Regarding the course that her child could possibly take, MP2 said, "Sa IT po siya puwede. Papasok po siya doon sa IT. Pag nag-college po siya, magco-college po siya. Makakarating yan. Parang gusto ko siya sa Google, yung mga ganyan." (A course in IT is suitable. He is fit for an IT course. When he gets to college... he will go to college. He will reach that level. I think I want him to work for Google, for companies like that.) AP 2 confirms that ADD 2 is indeed inclined to take up a computer-related course and study abroad. In contrast, others consider alternative educational paths such as vocational and livelihood training for their ADD.

Being productive despite the disability. Family members of adolescents with developmental disabilities still envision that they will acquire a job in the future regardless of their condition, developmental level and

academic skills. Their awareness of educational, vocational, and employment-related opportunities for PWDs gives them hope that their ADD could eventually transition into the community and the workplace. For instance, ADD 1's family members agreed that she has a lot of potential to learn and showed interest in being productive by getting a job later on. MP1 shared, "Kasi sa tingin ko naman sa kanya parang kaya niya naman magtrabaho. Kaysa puro aral-aral. Ano naman gagawin puro aral-aral na lang tayo? Dapat yung ano talaga na hindi lang hanggang katapusan yung aral niya." (I think she has the capability to work. Instead of always studying. What will she do, just to keep on studying? She should [be able to use her skills] and not just study without end.) She decided to continue to enroll ADD 1 at the PWD foundation's educational program and eventually apply for vocational training in housekeeping offered by their accredited partner institutions.

Family members have an idea regarding suitable occupations for their ADD based on their skill level, interest, and personal qualities such as being sociable and friendly. Others regard basic educational and daily living skills and proper social behavior as important to acquiring a job. The majority of the family members identified blue-collar jobs such as working as a housekeeper in a hotel and a massage therapist as possible careers. However, two family members (FP 3, GP 4) do not foresee that their ADD will become productive and gain employment. Father participant 3 (FP 3) is more concerned about the attainment of basic educational and daily living skills before considering employment for his son, saying that "Siguro last na iyon, ang sa akin yung basic lang muna. Siguro kapag na-achieve niya iyon saka nalang. (I will consider employment last. I want him to learn the basics first. I will think about that when he achieves the basics.)." On the other hand, GP 4 shared that her grandson will be needing constant assistance, thus foreseeing challenges to employment. GP4 said, "Yung pagdating sa [employment], yung maging productive siya, parang hindi ko na nafo-foresee na ganoon. Productive, yung magkaroon ng employment. Parang hindi, parang kailangan pa rin talaga na may assistance." (When it comes to being productive, I do not foresee that it would happen, that he would be

productive and gain employment. I do not think so, maybe he will need assistance.)

Families consider learning functional skills, whether through higher education, such as a college and vocational degree or just acquiring basic literacy, as a means towards getting a job and finding a source of income. Hence, families continue to strive to send their ADD to school. However, none of the families avail themselves of other intervention services to address behavioral and developmental concerns in language-communication, socialization, cognitive, self-help, and other skill areas.

## On being independent despite limitations.

Independence as a theme that signified family members' perceived well-being has emerged in four out of the seven families. For instance, GP 4 explained that she wants ADD 4 to be independent in the sense that he would be "self-reliant" and be able take care of himself. Also, she hopes that he will be able to commute short distances and engage in leisure activities like going to the cinema and watching movies by himself. GP 4 said, "Iyong kaya niya ihandle yung sarili niya. Sana nga yung kaya niya, pero hindi nakakatakot, eh. Mag byahe-byahe ba, iyong kaya niyang magpunta sa mall, manood mag-isa ng sine. (If he can at least be self-reliant, that would be okay with me." [I hope] he can handle himself. I hope he can travel, go to the mall or watch a movie by himself, but I am afraid to let him.)

Similarly, in the study of Uy-Tan and Adorio (2012), parents view independence as an important aspect of major life areas such as personal care, community involvement, recreational and leisure activity and independent living. Gaining independence will give them a sense of self-worth, allow them to lead normal lives and be productive members of society (Uy-Tan & Adorio, 2012).

In this study, most family members relate independence to basic functioning such as being able to tend to personal needs, establishing oneself in the future, securing a job and earning income, performing self-care and daily living skills with less assistance, engaging in leisure activities, and traveling short distances within the community. However, families

mentioned that ADDs need more training and hands-on opportunities on community living before allowing them to be on their own in public. The fears of family members regarding the safety of the adolescents when left unsupervised hinder them from giving more opportunities for adolescents to further develop their independence.

On living with dignity despite the disability. Two families expressed uncertainties about the future of their ADD. One mother participant did not express any concrete expectations for her son's life while her husband frequently thinks about their ADD's future. When asked to share their visions for the life of ADD 7, MP 7 and FP 7 have both expressed a lot of uncertainties. FP7 said that "Baka walang mag-alaga sa kanya balang araw." (Maybe nobody will take care of her in the future.) In a separate interview, MP 7 shared similar sentiments on this topic and shared:

Ewan ko kung ano ang maayos na buhay, wala nga akong iniisip kay ADD 7 na maayos na buhay kasi hindi ko alam kung sino ang magaalaga sa kanya na matatag tulad ko. Suntok sa buwan na lang, ang hirap. (I do not know what a decent life will be for ADD 7 because I do not know anyone strong like me who can take care of her. It is hard, I do not see any prospects.)

The parents' uncertainties and worries about the future stem from their concern that nobody will take care of their ADD, and that no place can ensure their welfare in case no family members are willing to do so.

Some parent participants associate their ADD's well-being with living with dignity by having a secured future. They do not want to depend on their ADD's siblings because eventually they would build their own families and lead their own lives. According to MP 7, "Hindi lang ako assured sa Ate niya kasi baka hanggang diyan lang siya. Mahahati din ang responsibilidad niya kapag may pamilya na siya. At saka hindi naman niya responsibilidad si ADD 7 kasi kapatid lang naman siya." (I do not feel sure about her sister caring for her. In the future, she has a responsibility to her own family, too. ADD 7 is not solely her responsibility

because she is only a sibling.) Although this sentiment was voiced out by MP 7, her action towards the sibling shows otherwise. She has become overprotective of the sibling to the point of interfering with her personal relationships and activities. According to SP 7, her mother is worried that she will leave their family and have no one else to depend on when caring for her sister and sick father.

Two mother participants in the study considered residential or institutional care as a possible living arrangement. MP 7 shared, "Sa mga pilay may lugar, yung matatanda may lugar, eh sila wala naman silang lugar, saan sila lulugar? Kung pwede ba sana may ganoong institusyon na mag-aalaga at mag-aaruga sa kanila. Kasi hindi naman lahat aarugain ng pamilya." (There are institutions for the physically disabled and the elderly, but there is no place for children like her, where will we take her. I hope that there is an institution that could care for them because not all families are willing to take them in.) For them, well-being meant that their ADD would live with dignity in a place where their needs would be met, and they would not be considered a burden to others. This perception deviates from common Filipino culture and family function because culture dictates that the family ensures the biological maintenance and protection of its members (Medina, 2015). Thus, responsibility over members with special conditions and needing welfare should still be covered by their family's obligations. These mother participants may not be aware of the harsh realities of residential care facilities (Graff, 2018) hence, the perception that these institutions would be a suitable place for their ADD.

## On addressing health and safety independently.

Being healthy and safe has emerged as a theme related to the well-being of ADDs in three out of seven families. Two families were very particular about their ADD's health during their early years because they were born with Down Syndrome and were very sickly. However, it was observed that parents do not pay as much attention to their medical concerns now as they used to. One family tried to maintain their daughter's health through proper diet and nutrition while the other took their ADD for check-ups, but the financial costs of check-ups, assessments, and treatments, poor accessibility

to healthcare, and the parents' lack of time to attend to health concerns were barriers to the maintenance of their ADD's health. MP 1 seldom allows her daughter to eat instant noodles, and when she does, she adds vegetables like *malunggay* (moringa leaves) to make it healthier. MP 1 shared, "Bihira lang din ako magluto ng [instant noodles], minsan nilalagyan ko ng malunggay. Ayoko naman araw-araw din niya kainin kasi baka magka-urinary tract infection siya." (I seldom cook instant noodles, I add moringa leaves sometimes to make it healthier. I don't want her to eat instant noodles daily because she might develop urinary tract infection.)

Based on observation, it can be said that ADD 1's diet may still be improved, for she takes coins from her savings and use these to buy snacks like chips and sweets from the store. She also likes fried chicken and meals from a local fast-food chain. In terms of her health, she did not complain about any health issues or got sick and sought medical attention during the observation period. On the other hand, MP 3 openly shared her struggle in caring for ADD 3 during his infancy, "Hirap na hirap ako diyan, wala akong panggastos." (I had a hard time taking care of him, I do not have money for medical expenses). She had to take him to the hospital for a check-up and laboratory tests every month. She lined up as a charity patient so they can avail themselves of free or subsidized services.

Now that ADD 1 is older and more aware of her surroundings, MP 1 and FP 1 have become more lenient and less worried about her. They allow her to visit their relatives who live nearby, run errands, and be mobile in their community because she is already familiar with the members of their community and knows her way home. They are not worried about her safety because ADD 1 keeps the front door locked, turns off the light, and unplugs electrical appliances before she heads upstairs to sleep. She also heeds to her parents' reminders to not let strangers and other children inside their home.

One family was concerned with the health of their ADD because his obesity had become detrimental to his overall well-being. MP 6 admits that she has a hard time implementing the prescribed weight loss program for ADD 6. She said that it is hard for her to deprive her son of food as a mother. MP 6 shared that:

Kapag pupunta sa doctor, hindi ko lang masabi sa kanila na hindi ko kayang tanggihan ang anak ko. Kung alam ko naman gustong gusto niya ibinibigay ko. Iyong feeling ko noon na parang na-dedeprive ka, inisip ko talaga ayoko mangyari ito sa buhay ng anak ko. (Whenever we visit the doctor, I could not tell them that I cannot say no to my son. If he wants something, I give it to him. I felt deprived when I was a child, and I don't want my son to experience that.)

MP 6 tries to limit cooking rice so that ADD 6 will lessen his carbohydrate intake. However, ADD 6 always finds and prepares something to eat when there is no food served on the table. Srinivasan et al. (2014) confirmed that children and adolescents with ASD are at high risk for obesity due to low physical activity levels, poor nutrition, medication use, metabolic abnormalities, and lack of knowledge or awareness.

Only one family was very attentive to their adolescent's health. The family ensured that their ADD has proper nutrition, opportunities to engage in sports and physical fitness activities, and medical care provisions from professionals. For instance, FP 4 is an active person who likes to exercise, engage in sports and eat healthily. He influences his son, ADD 4, to do the same. GP 4 adds that they are currently working on increasing the variety of food that ADD 4 eats. GP 4 said, "[Iniisip pa namin] Kung paano siya mapapakain ng variety of foods. Basta ayaw lang ng Tatay niya na mawawala yung saging at apple." ([We think about] how we can make him eat a variety of food. But his dad always wants him to have fruits like banana and apples in his diet.)

Likewise, in the study of Manlangit (2015), parents and guardians of developmentally challenged adults perceived exercise, physical activity, and social activity as primary priorities. The integration of social skills development and promotion of various degrees of social interaction from within the family,

community, and public settings were recommended to promote wellness. This family could provide for the maintenance of their ADD's health because the head of the family works overseas.

On the contrary, most mother participants in this study (5 out of 6 mother participants), despite facing financial difficulties, have opted to stay and devote their time and attention to caring for their ADD. Since most of these families belong to lower socioeconomic status, some mother participants compensate for the lack of finances by actively seeking funding from government agencies and private institutions.

On experiencing belongingness and being included in the community. Three families in this study perceived that being included in the community is important. FP 1 shared that unlike other children with special needs who were kept hidden at home by their parents, their daughter with Down Syndrome has been fully immersed in the community. She was free to navigate the nearby areas because she was already familiar with the place and knew her way home. Aside from this, their family's active participation in school and events organized for people with disabilities further exposed them to community affairs.

The other families relate community inclusion to having increased social awareness and understanding of disability because they are concerned about how other people would treat their ADD. For example, BP 2 thinks that his brother can somehow manage on his own because he attends a public school, but he shared that he is more concerned about how other people will treat ADD 2. He recalled an instance when he noticed that his brother had a bruise when he came home from the computer shop. BP 2 shared that it seemed like somebody pinched him. He was not fully aware of what happened because ADD 2 did not report any incident. BP 2 shared, "Wala namang problema kung pumasok siya sa normal school, ang problema lang talaga yung ibang tao kasi hindi nila naiintindihan. Mapapahamak siya kapag ganoon." (I see no problem if he attends normal school, but the real issue is that other people do not understand his condition. He could get into trouble.)

Further, he shared that ADD 2 is prone to be bullied due to his condition and that he (ADD 2) has not told them yet about such instances that he may have been bullied. For BP 2, increased social awareness and understanding must be present to help adolescents with disabilities become fully integrated and thrive in the community. He suggested that promoting social awareness and understanding can also start at home.

Social acceptance and community integration were included among the aspirations of parents for their children with ASD (Bernal, 2011). Parents perceive future challenges but remain hopeful that their children will be successfully integrated into the community and live independent and fulfilling lives.

Raising one's own family beyond the limitations of disability. Getting married and raising their own family is a theme that emerged in two out of seven families in this study. Some family members said that they keep an open mind regarding the possibility that their ADD would eventually find love and build their own families later on, while one father participant hopes that his daughter would find a companion in life. For example, CP 1 was first to bring up the idea that ADD 1 may have the potential to raise her own family. She said that she has seen people with disabilities having partners, getting married, and starting their own families on various social media and mass media platforms. She also mentioned a neighbor who seems to have cognitive disabilities but has a family of her own. These influence her perspective that being involved in a relationship and having a family is possible for ADD 1.

FP 1 also keeps an open mind regarding the possibility of his daughter having a partner in life and a family, he jokingly shared, "Kung makakaya niya. Kasi meron din naman talagang nag-aasawa na ganyan. Sabi ko nga sa kanya eh, Nak, ano mag-asawa ka ba? Bigyan mo kami ng sampung apo." (If she can manage. Because there are others like her who get married, I even tell her, Nak, do you want to get married already? Give us ten grandchildren.)

MP 1 shares the same sentiments but says that they have yet to see their daughter fall in love and wonders how she would act. FP 1 comments that ADD 1 is still young, so she will probably feel such emotions when she turns 18 and develops further emotionally. Similarly, according to Bernal (2011), having a family life is among parents' aspirations for their children with autism.

For AP 2, becoming independent is a step towards building a family life. She has also emphasized the need to "train" her nephew's potential partner to enable that person to understand his condition and effectively deal with him. Ryff (1989) shared that positive relations with others by exhibiting strong feelings of empathy and being capable of greater love, deeper friendship, and identification with others were identified as a criterion of maturity. Relationships are built on interdependence and formed through interaction (Johnson, 1993), thus for the ADD, attributes of their condition such as behavioral manifestations, and social and verbal limitations may lead to poor quality of relationships.

Three families in this study have not identified this theme because they envision their ADD to be living with them for life. In the case of ADD 3, MP 3 and FP3 anticipate that they will care for him until adulthood. Although he has siblings, they do not want to depend on them in the future. FP 3 said, "Siguro sa amin na talaga siya. Kasi yang dalawa magkakaroon yan ng sariling pamilya, ganon na talaga. Kasama na namin siguro. Parang hindi ko na ineexpect na magkaka-asawa siya." (Maybe he will continue to live with us because his siblings will eventually have their own families. I am not expecting that he will have a family of his own.) For these families, their ADD's well-being is tied to being with the family and not towards building their own family.

# Developing spirituality and trusting in God's provisions despite the challenges of the disability.

Two families identified having faith as related to the well-being of their ADD. One family was observed to have strong religious beliefs and affinity to their local church, while one mother participant anchored on her faith to get through their difficult family situation. In the study of Samaco-Zamora and Fernandez (2016), they said that Filipinos turn to worship and religion to sustain themselves in challenging economic conditions. Praying and worship were found to relieve stress and anxiety in the face of adversity.

For FP 4, spirituality must be an integral part of his son's life and well-being. He credits his mother, GP 4, for nurturing ADD 4's spirituality and affinity to their church. FP 4 shared:

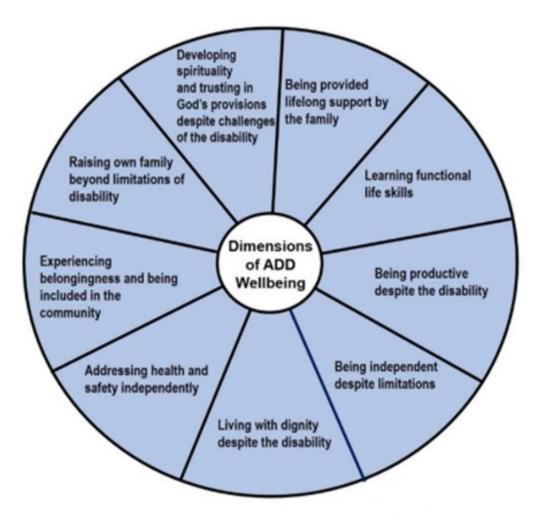
Sa spiritual palagay ko kumpleto na ako, eh. Last time noong nasa church, kilala siya sa buong church namin. Pag nag pa-birthday ako talagang lahat ng church [members] nandoon. Gusto ko doon na lang pumapalibot ang kanyang buhay which is very good, di ba? (In relation to the spiritual aspect [of his life], I believe that it is already complete. When I throw birthday parties for him, our church members are present. I want his life to be centered on his spirituality, which is very good, right?)

Likewise, AP 2 considers the development of the spiritual aspect as important. She credits the PWD foundation for introducing bible teachings and values to her nephew. AP 2 said, "Sa akin importante kasi iyon sa lahat ng bata yung madevelop mo yung spiritual aspect." (For me, the development of the spiritual aspect is important for all children.) Based on observation, ADD 2 shows interest and listens to the bible stories presented in class. He participates during simple discussions by answering the teacher's questions regarding the story. Research supports the contribution of spirituality to the physical and mental health of individuals. According to Elmer, Macdonald, and Friedman (2003) as cited in Swani (2018), spirituality promotes physical health, lowers diseases and lengthens life span through receiving increased social support from religious groups, developing improved personal coping skills through prayer and deep faith as well as by minimizing depression for the elderly through religious involvement.

## The Well-being of ADD through the Lens of Filipino Families

Through this multiple case study involving seven Filipino families, perceptions of family members regarding the well-being of their ADD revealed nine dimensions that represent culturally valued well-being outcomes. These dimensions are presented in the framework below (Figure 1).

**Figure 1**Dimensions ADD Well-being in the Context of Filipino Families



Dimensions of ADD Well-being. Family perceptions on the well-being of adolescents with disability include: (1) being provided lifelong support by the family, (2) learning functional life skills, (3) being productive despite the disability, (4) being independent despite limitations, (5) living with dignity despite the disability, (6) addressing health and safety independently, (7) experiencing belongingness and being included in the community, (8) raising own family beyond limitations of disability and (9) developing spirituality and trusting in God's provisions despite challenges of the disability. These dimensions present key elements that families would like their ADDs to possess, experience, and access to ensure that they will lead meaningful and fulfilling lives.

Figure 1 presents specific and descriptive well-being dimensions that are associated with valid life and future outcomes for Filipino adolescents with developmental disability such as learning functional life skills, living with dignity despite the disability and addressing health and safety independently, being productive despite the disability instead of suggesting general quality of life dimensions such as education, health, personal security and jobs that may also apply to typically developing adolescents and the general population. These perceived well-being dimensions emphasize that families aspire for their ADD to attain and experience these outcomes despite their limitations and challenges. Families also attach their personal notions and definitions to these dimensions, making it relevant and specific to their current family experience. Second, well-being dimensions such as being provided lifelong support by the family, being independent despite limitations and developing spirituality, and trusting in God's provisions despite challenges of the disability are culture-specific to Filipino families. As

mentioned in existing literature, Filipino families are said to be close-knit and accepting of their responsibility to ensure the welfare of all family members (Medina, 2015). Although independence emerged as a dimension of well-being, families only relate it to performing daily living and personal care activities with less assistance and navigating the community with less supervision, but their notion of independence does not yet encompass components of self-determination such as autonomy. This may be explained by the Filipino families' caring and nurturing quality as noted in this study which makes them fearful about allowing their ADD more opportunities for independence. Moreover, the limitations posed by disability are barriers to making the ADD capable of actions and decisions to improve his or her quality of life and developing this would require opportunities for choice-making, decision-making, problem-solving and other related skills to be provided to the ADD.

## Summary, Conclusions, and Recommendations

This qualitative research explored the perception of families and the ADD themselves on well-being. Through a multiple case study and two levels of thematic analysis, several themes on family perception of the well-being of ADD were identified.

The families' perceptions of the well-being of ADD were related to various positive individual and social outcomes. Fundamental to the well-being of ADD is the presence of the family throughout their lifespan and being provided with lifelong support. Contextual factors such as socioeconomic status, religion, family structure and the nature and severity of the disability of their family members also gave rise to varied family perceptions on the well-being of their ADD. Perceptions were also influenced by personal family experience such as being a sibling to a person with a disability, awareness about the potential of their adolescents and their developmental level, their parental involvement, awareness of available opportunities, awareness of successful life stories of other people with disabilities, and social media.

This study would like to put a spotlight on the importance of well-being and ways to promote it. Based on the findings, the following recommendations are put forth:

**Program Formulation.** Filipino families must determine their ADDs perception on their personal well-being through listening to their ideas, and careful consideration of their interests, existing skills, and other qualities. They must reflect on their goals for their ADD, their initiatives to foster these, and the resources available to their family. Educators and intervention partners may support families by providing guidance in the preparation of individualized transition plans (ITP) and wellness plans geared towards educational and lifelong well-being goals. Incorporating exercise, sports, arts, and physical activity in lessons, organizing webinars on the topic, and providing lectures on developing and designing well-being/wellness plans, and individualized transition plans (ITP) could be done by professionals to promote well-being.

The community sector (e.g. PWD organizations, government) may continue to promote social awareness, inclusion, and the rights of people with disabilities. They can provide family-centered programs geared towards developing positive relationships among family members, provision of respite care for parents/caregivers, counseling, and behavior management training for family members. The government may also consider providing social security, financial assistance, periodic assessment, therapeutic interventions, vocational and livelihood training, lifestyle and fitness programs, and regular health monitoring for ADD because families have expressed that these needed services are scarce and difficult to access.

**Policy Development.** Policymakers from the education, health, and social sectors need to work cooperatively to devise policies and plans that integrate well-being goals to support families and adolescents with developmental disabilities toward adulthood.

Knowledge Generation. Future researchers may replicate this study with a different set of respondents to validate findings and determine other possible dimensions indicative of well-being in the local context and strive to extract deeper insights and perceptions from persons with disabilities by using appropriate methods and data collection instruments.

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