

## Unveiling Shadows: Stigma Among Family Members of Children With Trisomy 21



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**ABSTRACT:** The experiences of family members of children with Trisomy 21 revealed the stigmatization these families face. This stigma arises from a combination of societal and cultural factors, mainly driven by people's tendency to judge based on physical appearance. Participants pointed out that the focus on facial features, where visible differences trigger prejudice, often leads to hurtful name-calling and exclusion. Additionally, a lack of awareness about Trisomy 21 in communities significantly affects families. Limited knowledge creates misunderstandings resulting in judgment and emotional distress. Disparities in education add another layer to the issue, as educational gaps foster unconscious biases and negative stereotypes. The data show that people's attitudes contribute to ongoing stigma.

The uniqueness of this study is that it explored the pervasive stigma experienced by family members and extended family members of children with Trisomy 21, commonly known as Down syndrome. Through qualitative interviews, the researchers were able to investigate the stigmatization and prejudices faced by these families. The findings revealed that stigma manifests in various forms, including social exclusion, discrimination, and emotional distress, significantly impacting the psychological well-being and social integration of both the children and their family members. Through these experiences that were highlighted, it helped to create the themes. By examining these experiences, the study recommends for urgent need for raising awareness, inclusive policies, and supportive interventions to mitigate stigma and promote a more accepting and understanding society. Future research on the stigma faced by family members of children with Trisomy 21 may also delve deeper into the different cultural and regional contexts that influence the stigmatization that these families encounter. Future studies may examine how effective different laws, anti-stigma programs, and awareness programs are in order to promote a more inclusive and welcoming environment for these families. The data that were gathered highlights the need for raising awareness and the government giving more focus to these people to foster empathy and reduce the negative perceptions associated with Trisomy 21.

**KEYWORDS:** Stigmatization, Trisomy 21 (Down Syndrome), Prejudice, Discrimination, Stereotype

### I. INTRODUCTION

According to Webster's Dictionary, a syndrome is a collection of signs and symptoms that co-occur, defining a specific abnormality or condition. Trisomy 21, as outlined by the Centers for Disease Control and Prevention (2023), is a result from an additional chromosome in the genetic makeup. Chromosomes are the little "packages" that make up genes in the organism. In Trisomy 21, one chromosome fails to separate correctly during cell division, leading to three copies (or an extra partial copy) of chromosome 21 instead of the typical two. This additional chromosome disrupts normal development of the brain and physical features. Trisomy 21 is another name for "Down syndrome" and a medical word for having an extra copy of a chromosome.

As asserted by the Down Syndrome Association of the Philippines Inc. (DSAPI) in 2014, over 100,000 Filipino households are living with individuals with Trisomy 21. Statistics reveal that approximately one in every 800 babies born in the Philippines is diagnosed with Trisomy 21. Individuals with Trisomy 21 typically display distinctive facial features, small hands and feet, and a single palm crease. They are at a heightened risk of medical conditions, experience delayed development, and may encounter behavioral challenges like attention issues and tantrums. Common issues include growth problems and speech delays, and a small percentage may also have autism spectrum disorders affecting communication and social interaction (National Library of Medicine, 2020). Given the widespread and deeply rooted stigma associated with Trisomy 21, the responsibility of caring for a child with this condition becomes a formidable challenge. Goffman (1963) defined stigma in classic terms as an "attribute that is deeply discrediting." This discreditable attribute can be overtly visible, like skin color or body size, or concealed yet still discreditable when disclosed, such as a criminal record or struggles with mental health. According to Goffman (1963), stigma is a pervasive aspect of social interactions, adding complexity to everyday micro-level engagements. Those with stigmas may

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approach interactions cautiously with non-stigmatized individuals, while those without a specific stigma may exhibit disengagement, excessive compensation, or attempts to ignore those who are stigmatized.

The concept of "enacted stigma" expanded upon Goffman's (1963) paradigm, referring to the actual prejudice and discrimination experienced by individuals with stigmatized traits. Enacted stigma is influenced by a combination of structural, social, and cultural factors. Negative stereotypes and prejudices within a society contribute to the formation of biased attitudes, leading to discriminatory actions. When individuals with stigmatized characteristics deviate from social norms, they face marginalization and exclusion, intensifying the impact of the process. Enacted stigma, as defined by Link and Phelan (2001), involves social processes that deliberately aim to avoid or exclude someone from social interaction. This is commonly seen through social distance, a significant behavioral marker reflecting the repercussions of stigma. Social distance delineates the difference between stigma, linked with social rejection and exclusion, and status, associated with influence and prestige.

In the Philippines, the way people view individuals with Trisomy 21 is significantly shaped by social and cultural dynamics. Cultural norms and traditional beliefs may lead to misunderstandings about the condition, creating obstacles to acceptance and comprehension within the community. Masanda's (2019) research revealed that parents' perspectives toward their children with Down syndrome were impacted by their cultural background, religious convictions, and the accessibility of resources. The study underscores the significance of culturally tailored interventions and support services to assist families in addressing the difficulties they encounter. Moreover, the stigma surrounding Trisomy 21 persists due to a lack of awareness and understanding about the condition. This lack of knowledge hinders the development of inclusive policies and services, posing challenges for families seeking resources and support. In 2002, former Philippine President Gloria Macapagal-Arroyo proclaimed February as the National Down Syndrome Consciousness Month through Proclamation 157. This initiative, led by DSAPI, encourages collaboration from various government departments and NGOs to promote awareness and understanding of Down Syndrome nationwide. The aim is to educate the public about the immense potential children with Down syndrome have to lead fulfilling lives (Philippine News Agency 2023).

Stigmatization is a complex and often overlooked issue. While existing research has mainly focused on the experiences of individuals with Trisomy 21, little attention has been given to the struggles faced by their families, including parents, siblings, and extended family members. This research aimed to explore the elements contributing to stigma among family members of children with Trisomy 21. It sought a deeper understanding of the elements influencing stigmatization, considering aspects such as family attitudes, cultural influences, and social interactions. Additionally, the researchers aimed to assess how enacted stigma impacted the presence of stigmatization among family members of children with Trisomy 21. By comprehensively grasping these elements, the study aimed to mitigate the stigma faced by these families, ultimately enhancing their everyday lives and promoting social integration.

In essence, this research sought to address the following questions:

1. Why do family members of children with Trisomy 21 experience stigmatization?
2. How do family members of children with Trisomy 21 experience stigmatization?
3. What elements contribute to this stigmatization, considering societal and cultural aspects within the community?

## II. FRAMEWORK OF THE STUDY

In order to examine and comprehend the different aspects of stigma in the given context, the researchers employed one well-known theory. The Stigma Theory developed by Erving Goffman examined how people who possessed traits or conditions that were socially stigmatized navigated their identities in the face of prejudice. According to Goffman, stigma was a social phenomenon that included discrimination, stereotyping, and labeling. In the end, the stigmatized person's identity was "spoiled" in the eyes of others. Goffman's Stigma Theory could be used in the context of Trisomy 21 to comprehend how societal perceptions and stereotypes might affect family members of a child with the condition, potentially resulting in stigma. According to the theory, people who were linked to stigmatized conditions might run into prejudice, discrimination, and social exclusion. While navigating societal expectations and judgments related to Trisomy 21, family members might have encountered stigma. In the context of stigma, the theory highlighted the significance of social interactions and the symbolic management of identity.

## III. METHODOLOGY

### Research Design

The type of research design that the researchers used was qualitative. The goal of qualitative research is to develop a deep understanding of the meaning and experiential aspects of human lives and the social world (Fossey, 2002). The research design that the researchers integrated was a case study, a detailed study of a specific subject, such as a person, group, place, event,

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organization, or phenomenon (McCombes, 2019). According to Yin (2009), it was an empirical inquiry that investigated a contemporary phenomenon in depth and within its real-life context, especially when the boundaries between phenomenon and context were not clearly evident. Lastly, the type of case study that the researchers utilized was a single case study, a research design that entailed a thorough examination of a single, exceptional case, often employed to produce profound insights and understanding about that particular instance. Stigma is a complicated and heavily context-dependent experience. A single case study enabled a thorough examination of the particular circumstances surrounding a single family, providing insights into the distinctive elements that either exacerbated or lessened stigma. The researchers were better able to identify the family's particular strengths and challenges by using a single case study, which helped them gain ample information that could be helpful in succeeding in this study.

### **Research Locale**

The research was conducted in Leyte – a province located in Eastern Visayas that is composed of 40 municipalities, one (1) highly urbanized city, and two (2) cities (PhilAtlas, 2024).

### **Research Participants**

The participants of the study were family members of children with Trisomy 21 in Leyte. The participants in the study were five family members each from three households with a child with Trisomy 21. The researchers used purposive sampling; a non-probability sampling technique appropriate for the nature of the study (Nikolopoulou, 2022). The researchers selected participants for this study based on the following criteria: (1) a member of the family, including parents, siblings, and extended family; (2) a family member who currently resided with a child who had Trisomy 21 (ages 18 and above); and (3) a family member who was willing to participate in this research.

### **Sampling Technique**

The sampling technique that the researchers used in this study was purposive sampling, a non-probability sampling technique appropriate for the nature of the study (Nikolopoulou, 2022). The study chose participants who could offer valuable context-specific insights since it examined the elements influencing stigma among family members of children with Trisomy 21.

### **Research Instrument**

The semi-structured interview method was used by the researchers. A semi-structured interview had been referred to as a 'conversation with a purpose' (Burgess, 1984). This kind of instrument allowed the researchers to obtain in-depth information on the experiences and perspectives of families of children with Trisomy 21 and to investigate stigma-related elements. The semi-structured methods enabled a thorough examination of each member's unique experiences and perspectives. A semi-structured interview offered the chance to delve completely into family members' personal stories, feelings, and ways of coping, as they might have had varied and complex views on stigma. Open-ended questions were used by the researchers to allow individuals to express their ideas, emotions, and experiences in a manner that suited them. This might have resulted in a greater understanding of the variables affecting stigma and the ways in which these variables appeared in various family situations.

### **Research Procedure**

Before conducting the study, researchers approached families of children with Trisomy 21, provided them with consent forms, and politely sought their approval to participate. Establishing open communication and rapport with the families was paramount to fostering meaningful dialogue. In accordance with ethical guidelines, informed consent was obtained from each participant, explaining the research's objectives, methodologies, potential risks, and benefits. Preliminary questions were also asked of the participants, including their background and information (i.e., educational, economic, etc.). Participants were informed of their right to withdraw from the study at any time without facing consequences. To ensure confidentiality, pseudonyms were employed in reporting and analysis. This was generally regarded as an important ethical safeguard to prevent the identification of individuals who contributed to the research (Taber, 2013). Once the researchers and the participants had established good communication, they started the collection of data using qualitative research methods to gain a comprehensive understanding of the issues at hand, considering the experiences and perspectives of the participants. The interview questions were translated into Bisaya and Binisaya (waray-waray). It was crucial to translate the questions to ensure accurate comprehension and minimize the risk of misinterpretation or omission of important information, as highlighted by Tuncer (2023). Purposive sampling was employed to select participants, and semi-structured interviews were conducted to glean pertinent insights. Specifically, researchers investigated the elements contributing to stigma among family members of children with Trisomy 21. Through this process, researchers anticipated uncovering valuable insights into these influential elements, ultimately enriching their understanding and informing potential interventions.

### **Ethical Considerations**

The researchers were committed to following the ethical guidelines outlined in the Belmont Report (1979) as they conducted the research. Respect for people was very important, and the researchers obtained all participants' voluntary and informed consent,

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ensuring that they understood the nature and implications of their participation. The researchers provided an informed consent form that outlined the precise benefits, guarantees, and risks of taking part in the study, along with the participants' ability to discontinue participation at any moment. They provided participants with straightforward information about the study. In addition, researchers respected each individual's autonomy and privacy while maintaining the confidentiality of sensitive information, ensuring that data was stored securely, and the identities of individuals were protected. They strictly adhered to Republic Act 10173, or the Data Privacy Act of 2012, in securing and protecting individual personal information. In particular, the researchers understood the vulnerabilities of certain populations and took special precautions to protect their rights. Beneficence directed the actions of the researchers, and they worked diligently to maximize the advantages of the study while reducing potential harm. The researchers were committed to fair participant selection, ensuring that burdens and benefits were distributed equally. The study was intended to have both scientific and social significance, contributing meaningfully to knowledge and societal well-being. Justice was central to the methodology of this study, and the researchers were committed to a fair distribution of benefits and burdens, inclusive participant representation, and equal access to the results of the study. Through these ethical considerations, the researchers aimed to conduct research that respected the rights, autonomy, and well-being of all participants. On the whole, researchers maintained the highest level of objectivity in their discussion and analysis of the collected data in order to prevent any types of bias that could distort information. In the process of analyzing the information collected from the participants, no part of the information was altered to avoid creating bias, jeopardizing the integrity of the study, and eroding trust between researchers and participants. The data and information provided by the participants were interpreted and analyzed in an entirely honest way.

### **Research Reflexivity**

In qualitative research, the researcher actively seeks insights into study participants' thoughts and emotions (Sutton & Austin, 2015). To guarantee transparency and rigor in the study, reflexivity was essential for recognizing and critically analyzing the influence of researchers. Continuous reflexivity was necessary for preventing biases, from the formulation of questions to the interpretation of findings. In keeping with the significance of reflexivity in qualitative research, researchers were conscious of assumptions, participated in self-reflection, and recorded personal experiences (Finlay & Gough, 2008). By reducing personal biases, this method improved validity and reliability and encouraged an unbiased investigation of stigma among family members of individuals with Trisomy 21.

### **Data Analysis Method**

The data analysis in this study followed a systematic and rigorous process to extract meaningful insights from the gathered qualitative data. The collected interview data were transcribed verbatim and organized for analysis. The researchers utilized thematic analysis, a method commonly used in qualitative research, to find, analyze, and report patterns (themes) in the data (Braun & Clarke, 2006). Also, the researchers immersed themselves in the interview transcripts, becoming familiar with the data to gain a comprehensive understanding of participants' experiences. The codes were organized into potential themes based on their connections and relevance to the study questions. The themes were refined through iterative discussions among the research team. Themes and subthemes were classified to create a comprehensive framework that reflected the participants' experiences. This process entailed arranging themes into coherent patterns. Themes were interpreted according to the context of the research questions, theoretical framework, and relevant literature. To reach significant conclusions, the researchers conducted a critical analysis of their findings. To improve the study's validity, participants were given a chance to evaluate the summarized findings, allowing them to validate the accuracy of the interpretations and conclusions based on their responses. To reduce individual biases, the research team did peer debriefing and checking, provided feedback, and validated each other's interpretations. By following these rigorous data analysis processes and being reflexive throughout the research process, the researchers aimed to provide a thorough understanding of the stigma placed on the families of children with Trisomy 21.

## **IV. RESULTS AND DISCUSSION**

The study presents results through themes to understand participants' experiences from gathered qualitative data. Data were coded to identify patterns, which were then organized into themes and subthemes. Themes were refined through team discussions, creating a framework reflecting participants' experiences. This process involved arranging themes into coherent patterns, interpreting them within the research context and relevant literature. Critical analysis ensured significant conclusions.

### **Theme 1: Cause of Stigma on Family Members of Children with Trisomy 21.**

Stigma can have a significant impact on the social interactions of families with their extended community, neighbors, peers, and society at large (Link et al., 2001; Corrigan et al., 2004). It can lead to social isolation, discrimination, and prejudice (Puhl et al., 2007). It can also have a negative impact on mental health and well-being (Corrigan & Watson, 2006). For example, parents who are stigmatized for their mental health conditions may be less likely to share their experiences with their children (Stuber et al., 2006). Stigma is society's negative evaluation of particular features or behavior. Cultural beliefs that define certain conditions negatively may create tainted and discounted identities for affected individuals and their families. Varied dimensions of

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stigmatized medical conditions include the nature of an illness, its history, and attributed characteristics; sources of the creation and perpetuation of stigma; the nature of the populations who are perceived to carry the illness; the kinds of treatments and practitioners sought for the condition; and how individuals with stigmatized medical conditions cope with societal insults that endanger their personal identity, social life, and economic opportunities (Ablon, 2002).

### Subtheme 1.1 Physical Characteristics of the Child

Stigmatization remains a major issue for families of children with Trisomy 21. Understanding why this stigma exists is key to developing ways to support these families and create a more inclusive society. According to Cruz et al.'s (2019) study, 85 percent of Filipino parents of children with Down syndrome reported feeling stigmatized by others. This demonstrates how prejudice against these families is common, with parents experiencing feelings of guilt, sympathy, and exclusion due to the condition of their children. Additionally, Carlier et al. (2012) found that the facial features associated with Down syndrome influence stereotypes and attitudes. This means that children whose facial features are more noticeably associated with Trisomy 21 often face stronger negative attitudes.

**Participant 1:** *Facial la ada ito? Facial, ginkikinita iton hiya, ako man bagan naaano ako nade-depress ako kun gin kikinita iton hiya. Didto ha Tacloban, gin dadara namon bisan diin. Naka-usa ngani didto nangaga-on kami, "Uy, hagi hi iday hin-o tim upod ngadi? Ano nga aanhi ka?... Akon iton anak. [Is it just a facial? Facially, everyone is looking at her. I feel depressed when everyone is looking at my child. In Tacloban, we took her everywhere. We have even eaten there once, and people asked her, what are you doing here? Why are you here? ... It's my daughter.]*

**Participant 3:** *It iya itsura. Sugad heton pagpalit namon, "Ano't hira nagpapereho it mga nawong bagan magburugto." Bagan na di-discriminate hira. [His looks make people ask, what are they? Why do they look alike? They all look like siblings." It looks like they are discriminating.]*

**Participant 7:** *So usahay gin dodown it mga bata gin kukuan, gin susugad hiya nga "ay mongol-mongol". An iya facial kuan oo, an itsura. Tungod han akon...tambok man an akon, an akon Down Syndrome. Amo adto nga gin tatamay hiya gin kukuan. [Sometimes people will look down on my child; they call her "mongol-mongol." Referring to my daughter's appearance. Also, my daughter is being bullied because of her body.]*

**Participant 4:** *Iton iya attitude ba it iya pang-gios iba ha aton. [His attitude and behavior are different from ours.]*

These responses show that people pay a lot of attention to the facial features of children with Trisomy 21, often judging them negatively right away. The participants mention that most people tend to look at the face of their relatives who have Trisomy 21, leading to discrimination. Participants also emphasize that children with Trisomy 21 have different traits and sometimes face hurtful name-calling. This connects with Goffman's idea of "abominations of the body," where visible differences can cause stigma. According to Goffman's theory, this only shows how societal attitudes deeply affect families of children with Trisomy 21. The prejudice that the family members receive based on the look of their relative who has Trisomy 21 truly affects them; it makes them feel excluded, sad, and treated unfairly. This shows why it's crucial to raise awareness and encourage inclusivity to fight against this negative treatment from society.

### Subtheme 1.2 Education and Moral Character of individuals

Educational programs that teach about mental health, symptoms of disorders, and available treatments help dispel myths and misconceptions (Meisel, 2022). The participants recognize that there are internal factors influencing those that cause them stigma. The factors included are the disparities in education, attitude, behavior and their moral character. Moral character being a driving factor in influencing one's view point and reaction towards others. These factors are observed to be playing a key role in either increasing or decreasing the stigma.

**Participant 2:** *Syempre. Baga an edukado nga tawo nagpapakita ng na piging. May-ada na hatag hin kwarta. An didi an mga kuru-kulang hin edukasyon, syempre pagpabati may nakaka-down. Nagbu-bully gud kay natural. [Of course. The educated people that are present in the feasts, they would usually hand out money. While those that are lacking in education, they would of course would openly down [him]. Bullying is natural to them.]*

**Participant 8:** *Ha akon pagkita, dire kay ha mga edukado ngan hadi nga mga dire. Inin nagdedepende inen ha estado hit ira pagkatawo, ha ira batasan. So kuan la ito siring pa ha kinaiyahan. [On how I see it, it's not about being educated or being not. It would really depend on the status of their humanity, on their attitude. Or how I would call it human nature.]*

Engaging with stigma on an almost daily basis is a common occurrence for the family members of those with Trisomy 21, which in and of itself should not even be normalized. But discrimination will never be eliminated as long as human conflict still exists. As such, having multiple strategies would be the best intervention we could do at the moment. Understanding the nature of the stigma itself is a good strategy for facing stigma. You can't combat something you don't understand yourself. It was observed that

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there were multiple factors at play in influencing the stigma itself. But factors that are cultural or moral in nature are hard to replace as they are ingrained in the human nature of each person. As stated by the participants, the problem lies with those who stigmatize them, whether it be their own moral values, beliefs, or level of education.

### Subtheme 1.3 Community values and Cultural beliefs

This subtheme delves into how the beliefs and values within communities can contribute to the stigma face by families with Trisomy 21. Societal views on disability can be shaped by cultural norms and values. Lee et al. (2020) highlights how collectivism and religious beliefs can influence stigma surrounding mental illness, potentially extending to families with children with Down syndrome. Recognizing these cultural factors is essential for building inclusive communities that embrace diversity and dismantle stigmas.

**Participant 5:** *Mayda. An one time kasi nakuan it hiya, na-kagat hiya hin idu. As in nalapa it hiya ngadi. Maupay pa an mga drivers may malasakit kaysa han tagiya mismu han idu nga waray halos kumadi ha balay. Maupay pa an mga drivers may malasakit.* [Yes. One time, he was bitten by a dog. It was really severe. Drivers are even more compassionate than the dog's owner, who hardly comes home. Drivers have more compassion.]

This highlights the interplay between community values. The drivers' compassion reflects a cultural emphasis on empathy and social responsibility (Fiske, 2009). This aligns with communities that prioritize collective wellbeing and offer assistance to those experiencing distress. Conversely, the dog owner's inaction suggests a cultural attitude that prioritizes individual interests over communal care (Fiske, 2009). This can contribute to the stigmatization of individuals or groups perceived as requiring additional support. When communities prioritize individual concerns, those facing challenges may be seen as a burden, leading to social isolation and judgment.

## Theme 2: Multi-faceted Experience of Stigma Among Family Members

Stigma affects everyday social interactions, adding complexity to how people engage with each other (Goffman, 1963). Even with advancements in medical science and better knowledge of genetic disorders, society often holds onto old stereotypes and prejudices. The way society views individuals with Trisomy 21 can deeply affect the mental and social well-being of their family members. Parents, siblings, and extended family members often face ignorance and insensitivity, leading to feelings of exclusion and frustration. The stigma associated with Trisomy 21 stems from outdated beliefs as well as cultural and regional prejudices that still exist in many communities. Understanding how stigmatization works is key to creating effective support systems for these families.

### Subtheme 2.1 Emotional Distress

Stigma continues to be a big problem that affects the mental health and well-being of individuals and their families. With the stigmatization that the family members have been facing, we cannot deny the negative impact that these behaviors can have on the family members. The emotional responses to stigmatization are multifaceted, often encompassing feelings of sadness, frustration, anger, and isolation. These families live in a complex social environment where it is sometimes difficult to understand or accept the differences in their child or relative who has Trisomy 21. As a result, both the family and children may feel judged and excluded, which can have a negative effect on their well-being.

**Participant 4:** *Syempre kuan ka man. Labi na it kag-anak. Syempre imo anak tapos makaka-bati ka han mga negatibo ha gawas nga mga diri maupay para it imo anak or imo patud. Syempre ma ul-ol gihap ha kasing-kasing ngan ha pan huna-huna gihap.* [Especially if he is your son and then you hear negative comments about him, of course you will feel hurt. It hurts both my heart and my mind.]

**Participant 5:** *Syempre nag-iisog, na hu-hurt, nagtu-tuok kun danay.* [Of course, I get mad and hurt, and sometimes I cry.]

**Participant 7:** *Syempre nabibido ka as mother. Nasasaktan ka nga gin susugad it imo anak, kon puwede la tataguon nimo, dire nimo ipapakita ha mga tawo.* [As a mother, of course you feel hurt. Especially when people treat your son/daughter in such ways. If only I could hide it [the disability]]

**Participant 8:** *Ah, masakit na masakit na may mga tawo na nagsusugad hito. Pero natikaiha tanggap na ito namon, so nasiring nala kami "ah sige la kay ira man ito pagkilala, dire man kita hito puydi magkuan".* [Ah, it hurts so much that there are people doing that. However, as time goes by, we just accept all of it. We just say, "If they see my child as someone like that, then let them know we cannot do anything about it."]

Family members of children with Trisomy 21 often experience strong emotional distress due to societal judgment, as explained by Erving Goffman's Stigma Theory. Goffman shows how society's negative views lead to discrimination and isolation, causing these families to feel sadness, anger, and frustration. According to Ali et al. (2012), families tend to be the targets of social exclusion,

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with many reporting that they are avoided or treated differently in social situations. This exclusion can result in emotional distress for the family. This societal bias and prejudice come in different forms, from direct discrimination to subtle social exclusion, and can undoubtedly impact the mental well-being of these families. Goffman's theory helped the researchers grasp why these families feel this way. By understanding the societal origins of their emotional struggles, people can strive to create supportive environments that alleviate their burden and could create a positive environment for all, combating the stigma that these families have been facing.

### Subtheme 2.2 Manifestations of stigma in Daily Interactions

Stigma is subjective in nature. Research indicates that stigma is shaped by individual perceptions, beliefs, and experiences, which can vary across different contexts and cultures. A majority of the participants stated that they could observe the existence of stigmatization in their children's daily interactions. These stigmas can even affect them on a personal level.

**Participant 5:** *Pagmasulod hiya ngadtu ha ira balay, gin se-senyasan hiya nga gawas ngadi or gin kuku-anan ba hin facial expression nga ayaw didi, ayaw didi. Sugad hiton.* [When he enters their house, they would signal him to go out or they would instead use a facial expression that says, 'Not here, not here.' Something like that.]

**Participant 8:** *Masiring ito hira "ah kay kuan ito it ira mga ninuno mayda liwat hito, mana mana na ito ha ira" gindidiscriminate tam pamilya na lahi na ito namon.* [They would say that, 'Ah, that thing is because of their ancestors, they just inherit it.' They would discriminate our family that it's in our lineage.]

**Participant 2:** *Baga, ha akon nag-aalangan an iba pag-discriminate.* [They're hesitant to discriminate me.]

There are contrasting views among the participants based on the stigma they experience. The participants observe that some are confident in expressing their stigma to the family members of children with trisomy 21. But in contrast with the views of the other participants, there are those who still hesitant to openly express their stigma toward the family members of children with trisomy 21. A concealable stigma becomes an issue in that people might have to determine whether to disclose the information, which poses another layer of pressure (Pachankis, 2007; Quinn & Chaudoir, 2009; Siegel et al., 1998). As such, the level of confidence from those that stigmatize them plays a role in influencing the level of stigma faced by the participants.

### Subtheme 2.3 Regional and Cultural Disparities in Stigma Experiences

Stigma can be different depending on where you are and the culture, you're in. For example, a study by Reyes et al. (2020) found that families of children with Trisomy 21 in the Philippines often experience discrimination in places like schools, workplaces, and social settings, especially in places where most people are unaware of this condition. This shows how location and culture can affect how much and what type of stigma they face. In places where people don't know much about or accept Trisomy 21, families might deal with harsher judgment and exclusion, making them feel even worse. But in areas where there's more awareness and support, families might not face stigma as badly. This highlights that cultural and regional disparity can contribute to the stigma faced by families of children with Trisomy 21.

**Participant 3:** *Oo. Kun ha Samar, napapausa hira kun ano it sugad nga nawong. Kay Samar, kun nakadto kami hit iya Papa. Pero didi dire man.* [Yes. In Samar, people wondered why my son's face looked like that every time we visited his father. However, we do not observe the same treatment here.]

**Participant 5:** *Kuan. Depende. Kay for example, danay kasi may mga tawo liwat nga amon naka-halubilo so open-minded or mayda gihap hira uropod or relatives nga sugad. Ok hiya didto. Pero it iba kay di man maiwasan. So asya talaga adto. Depende na.* [It depends. For example, sometimes there are people we interact with who are open-minded or have friends or relatives in the same situation. It's okay there. But with others, you can't avoid the discrimination. So that's how it is. It really depends.]

**Participant 7:** *Oo usually, pero mayda mga places like ha supermarket gin kukuan gani hiya gin appreciate "hello, hello" sisiring hito hiya gin upod. Those people mga kuan la mga tawo nga specially educated people. Oo educated nga nasiring "hi" "hello", ginfri-friend hiya. Pero there are some people nga gin didiscriminate gud hiya pag kita "hala, iya anak sugad hito". Akseptado hiya dinhi, pero ha iba na lugar bagat dire pa.* [Yes, usually, but there are places like supermarkets where people appreciate her saying 'hello, hello.' Those people are educated. Yes, educated people are saying 'hi, hello,' and befriending her. But there are also people who keep discriminating against me and my child, saying, 'Oh, her child has that.' We are only accepted in some places.]

**Participant 8:** *Ah usually pag aadto kami suyard, ormoc, gusto namon na hiya mag enjoy, kumite han mga lugar na para malipay hiya. Super enjoy ito hiya pag nagkakat, napakadto ha mall, ha robinson para maglipay. Pero may mga tawo na nag oobserve na an iba na appreciate hiya, mayda gihap an ginkikinitaan hiya na bagat dire maupay. Dire ito maiiwasan.* [Whenever we visit places in a city like Ormoc, we want her to enjoy and appreciate the surroundings to make her happy. She really enjoys it when we go out, visit the mall, and go to Robinsons for fun. However, there are people who observe her differently. While some appreciate her, others look at her in a not-sonice way. This is something we cannot avoid.]

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Stigmatization can vary in different places depending on how aware people are of Trisomy 21. Families in regions with low awareness of Trisomy 21 are particularly vulnerable to this stigmatization. The lack of understanding can manifest in heightened judgment and exclusion, contributing significantly to the emotional distress experienced by these families. However, places that are more exposed to Trisomy 21 have more understanding and can show empathy and respect. According to Pusapati (2009), stigma against disabled children is a global issue and is often tied to cultural and religious beliefs. Additionally, negative attitudes vary by region, with lower-income areas having stronger negative perceptions compared to higher-income areas. Goffman explains that stigma not only lowers a person's value in the eyes of society but also leads to their social exclusion. In regions where acceptance is limited, families may find themselves excluded from social, educational, and even medical support networks, further intensifying their sense of isolation. This being said, it is indeed necessary to raise awareness and promote acceptance of Trisomy 21 across all regions. If everyone understands, people can make things better and create a more inclusive environment where families feel supported, and their children are valued members of society.

### Subtheme 2.4 Family Dynamics and Responsibilities

Raising a child with Down syndrome presents distinct challenges, yet families also discover profound strengths and positive experiences. Studies like Martinez et al. (2010) highlight the crucial role of family resilience in navigating these challenges. Strong family bonds and effective coping mechanisms contribute to a more fulfilling life for both the child and the family unit. While parents often face increased stress and require strong support systems, siblings can play a vital role as well. Research by Cuskelly & Gunn (2003) suggests that sibling relationships with a child with Down syndrome can be more positive and less competitive than those in typical families. Fostering strong family bonds and encouraging positive sibling interactions can create a more supportive and enriching environment for everyone involved.

**Participant 1:** *Kay siring ko man, "Kay kaya man namin, it amon anak.....Hit kami it nagbabantay ha iya.* [As I say, 'Because we can handle it, our child... We are the ones who take care of her.]

This reflects the strong emphasis on Filipino culture places on family responsibility, particularly when caring for a child with Down syndrome. This translates to a commitment to providing care, driven by the belief in family as a primary support system. This dynamic aligns with findings by Ancheta (2006) who highlights the centrality of family in Filipino culture, particularly when navigating challenges faced by individual members. Understanding this cultural context is crucial for supporting Filipino families with children with Down syndrome, as it emphasizes the importance of building upon existing family strengths and fostering a sense of community support alongside their inherent sense of responsibility. However, the experience of raising a child with a disability can be isolating for families, partly due to societal expectations around parenthood as outlined in Goffman's Stigma Theory (1963). This theory suggests that social norms dictate expectations for behavior, and those who deviate from these norms risk being labeled as "stigmatized". In the context of disability, parents encounter immense challenges that may make it difficult to fulfill these idealized parental roles. The pressure to conform to these expectations, despite the additional hurdles, can be a significant source of stigma. This can manifest as feelings of inadequacy or judgment from others, creating a sense of isolation for families who simply wish to provide the best care for their child. Understanding this dynamic is crucial for dismantling stigma and fostering a more inclusive society that celebrates diverse family experiences.

**Participant 6:** *Ang ako la kay kun mangalagas mi naa may mga igsoon. Ang mga manghod lay ako paku-anon...*[When we get old, he'll have his siblings anyway. I'll just leave him to his siblings.]

This highlights sibling taking on roles of stewardship within the family, especially in situations where parental inadequacy is a concern. Families with children with disabilities may experience a shift in sibling dynamics, with siblings assuming greater responsibility due to perceived parental limitations. This phenomenon, known as "sibling stewardship" (Hobbs et al., 2010), can influence family decision-making as siblings grapple with managing the complexities of stigma within the family unit. Societal expectations and cultural norms surrounding disability can further impact these sibling relationships, fostering a sense of obligation to support and protect each other from the negative effects of stigma (Hobbs et al., 2010).

### Theme 3: Coping Mechanisms and Support

Children with Trisomy 21 and their families can experience stigma due to misconceptions about the condition. This stigma can manifest in various ways, from social isolation to limited opportunities. Studies like Pettersson & McConkey (2018) highlight the significance of a supportive family environment. When communities embrace children with Trisomy 21 and their families, it fosters acceptance, challenges negative stereotypes, and creates opportunities for meaningful social interaction. Research by Turnbull et al. (2020) emphasizes the role of inclusive communities in creating a welcoming environment. Public awareness campaigns, as explored by Baird et al. (2021), can educate the broader population about the condition.



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### Subtheme 3.1 Coping Strategies in Response to Stigma

Coping with stigma can help to maintain a positive self-concept (Major & O'Brien, 2005) and self-esteem (Ilic et al., 2011). But, depending on the coping strategy, outcomes may differ substantially. The literature suggests that secrecy is associated with lower self-esteem (Ilic et al., 2011), higher levels of experienced discrimination (Lasalvia et al., 2013), perceived discrimination, and self-stigma (Vauth et al., 2007). In contrast, active strategies like educating others and challenging others were not associated with less self-esteem or feeling ashamed (Link et al., 2002). The participants shared their various strategies on how to cope with the stigma they faced. These strategies include special care and attention, acceptance, self-conditioning, and parental advocacy and support.

**Participant 5:** *Ngan syempre, it pagtrato namon ha bata, gin uupay namon hiya. Bagan nakuan nala kami, nabawi nala pagtrato hin maupay.* [And of course, on how we treat our children, we do our best. It's like, we're making up for it by treating them well.]

**Participant 3:** *Ha amon na tungod na natikaiha natatanggap nala namon it reaksyon hit mga tawo.* ["For us, as time passed, we just learned to accept the reactions we got from other people.]

**Participant 4:** *Syempre ano, naghihimo nala hin paagi nga diri mag-isip gud hadtun mga negatibo.* [Of course, I would instead just find a way not to think about those negative things.]

**Participant 6:** *Ako kuan... kung kuan sila sa akong anak ba, mo istorya sila nga mao na, sa amo la unta sila mo istorya, dire ang bata.* [For me, if they do that to my child, if they keep saying those things, they should have talked to me instead, not the child.]

Each participant has their own coping strategy for facing stigma. Coping strategies are crucial in facing stigma because they enable individuals to navigate and manage the challenges associated with stigma effectively. Although stigma coping orientations vary by context, individuals often choose to conceal problems, which is associated with greater anticipated and experienced discrimination and less confidence to challenge stigma. (Isaksson, A., Corker, E., Cotney, J., Hamilton, S., Pinfold, V., Rose, D., Rüschi, N., Henderson, C., Thornicroft, G., & Evans-Lacko, S., 2017)

### Subtheme 3.2 Government Effort and Public Awareness

Government efforts and public awareness campaigns can significantly impact how families raising children with Trisomy 21 navigate societal challenges. Increased awareness can foster empathy and understanding, while government initiatives can provide crucial support systems. Studies like Ahlborg et al. (2018) highlight the positive influence of awareness campaigns in reducing stigma toward disabilities. By working together, governments and the public can create a more inclusive environment for these families.

**Participant 7:** *Amo ito, there should be a kuan a calling or kuan ba an inin pamalaod. Government, there should be "No discrimination" it mga may Down Syndrome whatever mga abnormal...Gusto tagan hira hin attention han Government. Allocate funds for PWD.* [In my opinion, there should be a calling or laws. The government should enforce "No discrimination" against those with Down Syndrome or any other disabilities. I want the Government to pay attention to them. Allocate funds for PWD.]

This highlights the importance of a two-pronged approach involving legal and resource-based solutions. By enacting anti-discrimination legislation and allocating resources for PWD programs, governments can play a significant role in dismantling stigma and fostering a more inclusive society for individuals with Trisomy 21 and their families. This approach aligns with the concept of social inclusion, which emphasizes removing barriers and creating opportunities for equal participation in society for all individuals (Shakespeare, 2006). The participant emphasizes the importance of legal protections against discrimination and increased resources for Persons with Disabilities (PWDs).

**Participant 8:** *Kun mayda ka mga natutunan sugad hito pwede mo pa ngani ishare diba, educate an mga tawo. Educate talaga an tanan para ma lessen it diskriminasyon.* [If you have knowledge about it, you can actually share it, right? Educating people. Everyone should really be educated to lessen discrimination.]

Educational initiatives can increase knowledge about Trisomy 21, foster empathy, and challenge stigma, ultimately creating a more inclusive society. The participant emphasizes "educate" as a key strategy to "lessen discrimination." This aligns with the concept of disability awareness, which focuses on educating the public about the capabilities and experiences of people with disabilities (Bundschuh et al., 2001). However, the participant goes beyond mere awareness. It suggests a desire for a more empowered approach to education. This approach to education empowers not only the families but also the entire community. It creates a more informed and understanding public, lessens the stigma, and ultimately contributes to a society where individuals with Trisomy 21 are valued, respected, and have the opportunity to reach their full potential.

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### V. CONCLUSIONS

Family members of children with Trisomy 21 experience stigmatization due to a combination of societal and cultural factors, primarily driven by people's tendency to judge based on physical appearance. Participants highlighted the negative focus on facial features, where visible differences trigger societal prejudice, often manifesting in hurtful name-calling and exclusion. Furthermore, a lack of awareness about Trisomy 21 in communities significantly impacts families, as limited knowledge breeds fear and misunderstanding, leading to judgment and emotional distress. Disparities in education add another layer to the issue, with educational gaps fostering unconscious biases and negative stereotypes. The data highlighted that people's attitude might contribute to ongoing stigma.

However, the study also revealed a positive aspect of Filipino culture. The strong emphasis on family care, which creates a robust support system for families. This support, while beneficial, can also present challenges. Societal expectations may place undue burdens on siblings, highlighting a potential conflict between traditional values and individual needs.

Education emerges as a central solution in addressing stigma. Participants emphasized the importance of empowering not just families but the entire community through educational initiatives. This education should begin within families, fostering understanding and self-awareness. By equipping families and communities with knowledge about Trisomy 21, negative labels and misconceptions can be challenged.

Overall, addressing stigma requires a collective effort. Families, communities, and the government all have roles to play. By raising awareness, promoting empathy, and enacting supportive policies, people can create a more inclusive environment where children with Trisomy 21 and their families can thrive.

### VI. RECOMMENDATIONS

Families of children with Trisomy 21 often encounter profound emotional and social challenges due to societal stigma. This stigmatization can significantly impact their overall well-being, leading to feelings of isolation and frustration. The societal tendency to focus on the distinctive physical and developmental traits associated with Trisomy 21 contributes to a lack of understanding and empathy, further highlighting the difficulties these families face.

- 1. Public awareness campaigns.** Raising awareness is crucial to combating the prejudice and discrimination that these families have been facing. Awareness campaigns can educate the public about the realities of living with Trisomy 21. Through this knowledge, every community can begin to understand the different experiences and strengths of individuals with Trisomy 21 and their families. This understanding is needed for fostering an environment that is inclusive and supportive.
- 2. Government Action.** Legal protections and resource support may work together to help individuals with Trisomy 21 and their families. This is a big step in combating the stigma that they are facing in their daily lives. Enacting robust anti-discrimination laws is crucial for providing a legal safeguard against the prejudices and biases that these individuals often encounter. Such laws will not only protect their rights but also pave the way for people to realize that we are all born equally and no one deserves to be treated unfairly. Also, legal measures, such as allocating adequate resources for programs specifically designed for persons with disabilities (PWDs), are indeed essential. This includes funding for educational initiatives, healthcare services, and social support systems. By providing these resources, the government can help combat inequalities and foster a more inclusive environment for both the family and children with Trisomy 21.
- 3. Future Research.** Future research on the stigma faced by family members of children with Trisomy 21 may delve deeper into the different cultural and regional contexts that influence the stigmatization that these families encounter. Studies may also examine how effective different laws, anti-stigma programs, and awareness programs are in different communities to determine which areas need improvement to really create a safer environment, especially for family members and children with Trisomy 21.

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