

Original research article

Parenting Paradox: Exploring the Lived Experiences of Raising Young Adult and Twins with Down Syndrome in Mauritius

Vandanah Gooria^{1*}, Francis Simui²

1 Open University of Mauritius, Mauritius

2 University of Zambia, Zambia

* Correspondence: francis.simui@unza.zm

ABSTRACT

Aim: There is a paradox of challenges and development in raising a child with Down syndrome (DS). This research explores the lived experiences of Mauritian parents raising identical twins with Down syndrome and other young people with this condition. The study aims to examine positive and negative affect, resilience, cultural dynamics, and the interactions between child, parent, family, and community..

Method: The study employed a qualitative interpretive design guided by Family Systems Theory, examining relationships and structures within family dynamics and how the family environment supported coping efforts. Sixteen parents of young adults with Down syndrome, recruited from U-Link and Down Syndrome Mauritius, participated in semi-structured interviews through purposeful sampling. Thematic analysis was used to examine positive and negative parental experiences from different layers of relationships.

Results: Initially, parents described shock, confusion, stigma, and grief at diagnosis, but gradually developed resilience through community support, peer social networks, spiritual beliefs, and adaptive parenting strategies. While raising twins with Down syndrome, parents reported increased caregiving demands, experiencing a resilient paradox of grief and growth, but eventually their presence brought profound joy despite financial strain, limited access to inclusive services, and other challenges. In summary, families raising young adults with Down syndrome in Mauritius exemplify vulnerability, instability, and positive resistance.

Conclusion: Parents reported increased family cohesion, stronger social networks, and a growing sense of purpose, despite ongoing challenges related to stigma, access to services, and emotional fatigue. These findings call for sustained, multidimensional support systems and inclusive policies that recognize both the burdens and the transformative potential of parenting young adults with DS in resource-constrained and culturally diverse settings like Mauritius .

Keywords: Parenting paradox, Down Syndrome and Twins, Coping strategies, Resilience, Lived experiences, Mauritius.

Editor: Solomon Mekonnen

Article History:

Received: September 10, 2025

Accepted: June 08, 2026

Published: June 10, 2026

Citation: Vandanah Gooria, Francis Simui, Parenting Paradox: Exploring the Lived Experiences of Raising Young Adult and Twins with Down Syndrome in Mauritius. DCIDJ. 2026, 37:2. doi.org/10.20372/dcidj.921

Copyright: © 2026 by the authors.

This is an open access article distributed under the terms of the Creative Commons Attribution License

(<https://creativecommons.org/licenses/by/4.0/>), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work, first published in DCIDJ, is properly cited. The complete bibliographic information, a link to the original publication on <https://dcidj.uog.edu.et/>, as well as this copyright and license information must be included.

INTRODUCTION

Parenting a child with Down syndrome is a profoundly complex experience, often characterised by a paradox of emotional distress and growth. Historically, research has predominantly framed disability within deficit-based narratives, portraying families – especially parents – as overwhelmed by grief, isolation, and chronic stress (Grech, S. 2016; Raap, E., Weille, K.L., & Dedding, C. 2024; Mishra, S. 2025). While this perception is grounded in real challenges, it has overshadowed a growing body of literature that emphasises resilience, empowerment, and positive adaptation in families raising a member with disabilities (Van Riper, M. 2007; Nelson Goff, B.S., Monk, J.K., Malone, J., Staats, N., Tanner, A., & Springer, N.P. 2016; Desimpelaere, E.N., De Clercq, L.E., Soenens, B., Prinzie, P., & De Pauw, S.S.W. 2023). This study explores the lived experiences of Mauritian parents, examining how they construct meaning in raising twins and other young adults with Down syndrome, and delves into both the positive and negative dimensions of their parenting, encompassing emotional paradoxes, challenges, resilience, and growth trajectories.

Down syndrome, caused by the presence of an extra chromosome 21, remains the most recognised chromosomal disorder worldwide (Centers for Disease Control and Prevention, 2019). Individuals with Down syndrome often experience developmental delays, health complications, and unique learning profiles, which place additional caregiving demands and burdens on families (Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025; Hendrix, J.A., Amon, A., Abbeduto, L., Agiovlasitis, S., Alsaied, T., Anderson, H.A., Bain, L.J., Baumer, N., Bhattacharyya, A., Bogunovic, D., Botteron, K.N., Capone, G., Chandan, P., Chase, I., Chicoine, B., Cieuta-Walti, C., DeRuisseau, L.R., Durand, S., Esbensen, A., Fortea, J., Giménez, S., Granholm, A.C., Hahn, L.J., Head, E., Hillerstrom, H., Jacola, L.M., Janicki, M.P., Jasien, J.M., Kamer, A.R., Kent, R.D., Khor, B., Lawrence, J.B., Lemonnier, C., Lewanda, A.F., Mobley, W., Moore, P.E., Nelson, L.P., Oreskovic, N.M., Osorio, R.S., Patterson, D., Rasmussen, S.A., Reeves, R.H., Roizen, N., Santoro, S., Sherman, S.L., Talib, N., Tapia, I.E., Walsh, K.M., Warren, S.F., White, A.N., Wong, G.W., & Yi, J.S. 2021). In some African societies, including Mauritius, disability is often perceived as a form of divine punishment, karmic debt, or personal failure, fostering exclusion and shame within families and communities (Chitando, E., Ohajunwa, C. & Dube, K. 2025; Ndlovu, H.L. 2016). Over the past two decades, both academic and policy discourses have shifted from viewing families with a member who has a disability as victims of circumstance to recognising their capacity for resilience, personal growth, strengthened bonds, adoption of new life priorities, and positive transformation (Galán-Vera, I.Z., Robles-Bello, M.A., Sarhani-Robles, A., & Valencia-Naranjo, N. 2025; Barklı, A., & Doğan, A. 2025; Rakap, S., & Vural-Batik, M. 2024; Farkas, L., Cless, J.D., Cless, A.W., Nelson Goff, B.S., Bodine, E., & Edelman, A. 2019). This paradigm shift aligns with broader movements in disability advocacy that emphasise empowerment, inclusion, and dignity over charity and pity (Alshdaifat, S. 2025).

Mauritius, with its multicultural and diverse population, presents a distinctive context with varying philosophies and interpretations regarding how parents cope with raising their young adults with Down Syndrome, across different layers of social relationships and cultural environments. Approximately 59,870 people live with disabilities, including Down Syndrome, with 28,923 receiving basic pensions from the State due to invalidity (Statistics Mauritius, 2015 and April 2026). The country reflects both the challenges and opportunities of a transitioning disability landscape. Many report positive changes following the ratification of the UN Convention on the Rights of Persons with Disabilities (UNCRPD), and families often rely on informal networks and NGOs. However, socio-cultural taboos and infrastructural limitations still impede full inclusion (Lecomte, U., De Los Ríos Berjillos, A., Lethielleux, L., Deroy, X., & Thenot, M. 2024). The growing network of NGOs, such as U-Link and Down Syndrome Mauritius, is reshaping

the narrative by fostering peer support and advocacy. In the local context, the impact of disability on caregivers of young adults, especially identical twins with Down Syndrome, is rarely discussed. In Mauritius, little is known about (i) the lived experiences of parents with a family member who has Down syndrome (DS); (ii) the factors or enablers that empower them with effective coping strategies; and (iii) the related disablers or challenges they encounter throughout their parental journey. Given that the island does not have an established genuine data on individual with DS and their parents' lived experiences in place, it is critical to understand and unveil these experiences from different angles i.e. child, parents, family and community approaches in order to improve their needs and support for a more inclusive society in a developing country. Similarly, many previous studies examined how characteristic parenting styles were adopted by parents who raised a child with DS in relation to their level of coping with their children's adverse behaviours and constantly sought professional help (Celik, P., & Kara Uzun, A. 2023; Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025). But in this study, it focuses on the holistic approach of parenting dyad, emphasizing more on parent-child link and the entire interactive system across different levels: Child, Parents, Family & Community. Despite the ratification of the Convention on the Rights of the Children (CRC) and the mobilisation for the adoption of the CRPD in developing countries, people with DS and their families continue to face daily challenges. It is even more challenging in getting support to raise young adult with DS of families in Mauritius, thus leading to anxiety, societal stigma, a complex mix of acceptance, denial and this insufficient information and lack of advocacy for their inclusion, remain a continuous barrier till you end up with self-child understanding and thus parents requiring for the need of better communication, 'understanding the healthcare situation' and coping strategies (Gothwal, V.K., Bharani, S. & Reddy, S.P., 2015; Bottcher, L., & Dammeyer, J. 2025). Existing research has historically emphasized the negative outcomes of raising children with developmental and intellectual disabilities, including psychological strain, stigma, and social isolation. However, these perspectives often overlook the resilience, adaptive strategies, and positive affect that the parents develop over time. There is a gap in literature that captures the unique experiences of raising twins with DS, a statistically rare and emotionally nuanced circumstance. In Mauritius, where cultural beliefs, limited access to inclusive services, and emerging disability advocacy intersect, the lived realities of such families remain underexplored. There is a critical need to understand how these parents navigate the emotional, social, and structural challenges and how they draw meaning, support, and strength from their experiences to inform inclusive policy, family-centered intervention, and community support systems. Despite the increasing prevalence of individuals with special needs, there remains a dearth of localized, in-depth qualitative research that captures the unique socio-cultural, emotional, and practical challenges within the Mauritian context. This study is a novelty research based on parenting experiences while raising twins and young adults with DS in the country, leading to the acquisition of new and unfamiliar experiences, knowledge, practical and scientific progress in the context of disability. Academically, this study enriches the general discourse on disability, parenting, and family dynamics by incorporating perspectives from a developing island nation, which are often underrepresented in literature. Past research on families of children with DS reflected a pathological model such that families were naturally assumed to suffer as a consequence of a child with a specific disability. By adopting the Family System Theory (FST) in an event of disability of a family member, derive different meanings towards a positive contribution with the available resources including health, finance, social networks, support systems and belief systems. The study provides a valuable contribution in understanding family dynamics and how parents raising a young adult with DS, perceive his development as challenging and responding to the related

stress with available coping resources. Findings highlight the need for policy improvements, enhanced support networks and financial assistance programs tailored to families of adult with DS in Mauritius. By exploring the lived experiences of these parents, the study contributes to filling this gap in knowledge, offering critical insights into the paradoxical nature of parenting where profound joy coexists with intense stress, hope intersects with uncertainty, and resilience emerges alongside vulnerability.

Despite limited research focused solely on Mauritius, regional studies from the Indian Ocean and African contexts offer valuable parallels. A recent study by Soll, B.A., Oxenham, V., Kowlessur, S., Kassam, F., Bhoosun, O., and Reebye, R. (2025) examined disability perceptions in Mauritius, revealing limited medical care, isolation, cultural stigma, and inadequate community support for families, especially during the Covid-19 pandemic. These socio-cultural barriers increase parental stress and isolation, reflecting findings from similar island nations (Nimusiima, C., Kawesa, E. S., Seeley, J., and Mbazzi, F. B. 2024). Stigma, and the intersection of cultural beliefs and disability, remains a critical factor shaping parental experiences. Luetke Lanfer, H., Anderson, E., Bah, F., Krawiec, S., Rossmann, C., and Vines, A. (2025) documented that in many African and island societies, spiritual and traditional interpretations of disability influence both family coping strategies and societal acceptance, affecting access to resources and emotional support. This underscores the need for Mauritius-specific qualitative research to contextualise parenting paradoxes within its unique multicultural framework. The review synthesises studies to highlight paradoxical parental experiences, coping mechanisms, cultural influences, and the specific challenges of raising twins with DS. This study aims to synthesise theoretical and empirical literature on various types and levels of family influences in Mauritius, and to describe their perceived interrelationships through positive and negative dimensions across Child, Parents, Family, and Community. The discussions in this study focus on 'Experiencing Growth, Coping and Resilience' and 'Grappling with Stress, Stigma, and Structural Barriers'.

Family Systems Theory (FST) is widely adopted in psychology, therapy, and family studies, as it demonstrates how individual issues often reflect broader family dynamics rather than isolated problems. Grounded in Family Systems Theory (Turnbull, A. P., & Turnbull, H. R. 1990; 2001), this study examines how Mauritian parents understand, cope with, and ultimately grow through the experience of raising young adults and twins with Down syndrome. The research investigates coping mechanisms, resilience, social interactions, cultural interpretations, and structural barriers, providing a holistic and human-centred account of parenting in a multicultural context. In the scoping review (2017–2022), studies reported using a family framework, including strength, resilience, stress, coping, negatives, and challenges (Van Riper M, Cosgrove B, Fleming L. 2023). Recent studies continue to apply transactional and family systems models to explain how parents adapt to the dual demands of caregiving stress and emotional reward (Cunningham, C. 1996; Rutter, T.L., Hastings, R.P., Murray, C.A., Enoch, N., Johnson, S., & Stinton, C. 2024). Çaksen, H. (2025) highlighted the critical role of meaning-making and positive reframing in parents' psychological adaptation, showing that social support networks and culturally embedded coping strategies significantly influence well-being. Mishra, S. (2025) further demonstrated that parents benefit from tailored interventions that enhance resilience and reduce parenting stress, particularly when these interventions consider cultural and familial dynamics. These insights underline the importance of culturally sensitive psychosocial support to mitigate the paradoxical pressures faced by parents.

Grounded in FST, this study provides a comprehensive lens to understand the dynamic interactions and challenges within families raising twins and young adults with DS and posits that families function as emotional units where individual behaviors and

experiences cannot be fully inferred in isolation but must be seen as part of the larger family context. This theory illuminates how the birth of a child and twins with DS impacts family roles, relationships, communication patterns, and overall functioning, highlighting the interconnectedness of each family member's coping strategies. In line with Bornstein, M.H. (2019) and Wallis, A., James, K., & Rhodes, P. (2024), which underscore the importance of family systems approach about understanding 'the effect of relationships on relationships' and managing emotions and address the complexities of parents require dialogical reflective processes in the form of systemic therapeutic relationship of family, especially for those looking after young adult with DS. It recognizes that parenting a child with a special needs is not static but evolves through continuous transactions involving family dynamics, social support, cultural expectations, and external stressors. It also aids in unpacking how families negotiate challenges, adapt to stress, and construct meaning amidst the paradoxical realities of parenting young adult with DS. Guided by FST, the study focusses on how the members connect to form a family with a member with DS and reveals the way the family organize and interact among themselves. It is assumed that familial, community and social relationships are reciprocal and this theory guides the analysis in a systematic way while framing the family as an internonnected unit. The researcher highlights relational dynamics, boundaries, interdepending behaviours and tracking interactions with specific groups inside the family that are close to the young adult with DS, i.e parent-child dyad or sibling relationship. With this model, it enlightens the study to examine the positive and negative patterns and roles within a family having a member with DS to better address social, relational, emotinal and behavioral challenges. In this study, the parent, as a prime caretaker of a young adult with DS, is responsible for managing the emotional and practical needs of the latter and as well as other family members. While the parent's role seek to maintain family stability, foster trust and act as a mediator in conflicts and provide support during crises but they often neglect their own needs, thus leading to burnout and difficulty in asserting boundaries to run the household smoothly. Therefore, it is vital to explore the holistic exploration of parenting paradox, capturing both micro-level family interactions and macro-level societal influences that shape the lived realities of these parents.

Paradoxical Parenting Experiences

The jargon of 'parental paradox' in raising an individual with DS is highlighted into two-folds of phenomena, that is, parents' experiencing coexistence and contradictory emotions of stress, grief, tearful and joyful, well-being, uplifting and challenging. Parents from various studies (Skotko, B.G. Levine, S.P & Goldstein, R. 2011; Sheldon, J.P, Oliver, M. & Yashar, B.M., 2021; Vilaseca, R. Rivero, M, Ferrer, F. & Bersabé, R.M. 2020) demonstrated immense love, pride, strength, rewarding, personal growth and unique relationship with their child with DS and other disabilities whereas other studies (Chaudhry, N., Sattar, R., Kiran, T., Wan, M.W., Husain, M., Hidayatullah, S., Ali, B., Shafique, N., Suhag, Z., Saeed, Q., Maqbool, S. & Husain, N. 2023; Zhang, X.N, Zhang, S. Lui. C.Y., Ni, Z.H., & Lv, H.T. 2025; Rusu, P.P. Candel, O.S, Bogdan, I. Icius, C, Ursu, A. & Podina, I.R. 2025) showed several parenting challenges like psychological distress, social issues, increased demands and tension in the family environment and caregiving difficulties. Therefore, parents see themselves in a situation of a "paradox of the heart" where they simultaneously feel opposing emotions and desires such as grief and joy, hope and fear, social isolation, acceptance and desire to eliminate the disability (Ipsen, C. & Repke, M. 2022; Raap, et al 2024). From another school of thought, parents are able to maintain optimism and a sense of control in the maternal work and look like "embracing of paradox". According to research (Mishra, T.A, Pandey, K., Bhujel, B. & Adhikari, S. 2022; Alsamiri, Y.A. Alaghdaf, A.A. Alsawalem, I.M. Allouash, B.A. & Alfaidi, S.D. 2024), this paradox is manifested differently by both parents, at times, mothers reporting more

unhappiness in the initial caregiving years due to a greater burden of care on them whereas from other studies, fathers feel more confident in their parental role than in their professional roles. (Davies, A., Rix, J. & Robb, M., 2024; Langley, E. 2025). Mothers reported that their extended families often misunderstood the child's condition, which diminished their likelihood of seeking support from them (Yee, E.G.X, Folashade, A.T. & Perveen, A. 2025). From past studies, (Safe, A., Joosten, A., & Molineux, M. 2012; Woodgate, R.L, Ateah, C. & Secco L. 2008; Sharpley, C. F., Bitsika, V., Efremidis, B. 1997) there were also a strong paradox of sentiments where parents highlighted 'frustration of finding the right support', 'mother as therapist', 'supporting their wider family and partner', 'father mental health', 'flexible employment', 'grief associated with the ambiguous loss of normalcy', 'to live a valuable life' and 'normal life'. Caregivers reported 'knowledge deficit' and being routinely met with a lack of understanding about the types of disabilities, indifferences and their respective characteristics regarding the diagnosis, insensitivity and meeting their child's distinct needs, and, at times, rejection or stigma (Safe, A. & et al. 2012; Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. 2025). Recent literature validates the persistence of parenting paradox while extending understanding of specific factors impacting parents of twins with DS and those in culturally complex environments. The current study aims to address this gap by providing an in-depth exploration of these parents' lived realities, thereby enriching the global discourse with localized, culturally sensitive insights. This will inform targeted interventions and policies tailored to the needs of families in Mauritius and those in the similar settings.

The complexity of parenting twins with Down syndrome has received increased attention in recent years, although empirical studies remain limited. Medical professionals note that the likelihood of both twins being born with Down syndrome is exceedingly rare. This study is notable for including a rare case of identical twins with Down syndrome, a condition estimated to occur in approximately one in 1 to 5 million pregnancies (Brown, G. 2022). The experiences of these parents, who navigate not only the demands of caregiving but also societal curiosity, twin-specific challenges, and spiritual reframing, offer valuable insight into the dualities of pain and pride, limitation and love, that define the parenting paradox (Yee, E.G.X., Folashade, A.T., & Perveen, A. 2025). According to Niedbalski, J. (2025), individuals with twin siblings who have profound intellectual and multiple disabilities tend to be more family-oriented and mutually supportive. Niedbalski identified financial strain, time management difficulties, and emotional exhaustion as primary challenges in one of the few recent comprehensive analyses. Research indicates that parents of twins require specialised support programmes to address the compounded demands distinct from those faced by parents of a single adult with Down syndrome. Additionally, various studies highlight the importance of including sibling dynamics and family-wide coping processes to better understand how raising twins with Down syndrome affects overall family functioning. According to Steed, L. C., and Langlais, M. (2025) state that in the context of FST, if there is a lack of support for individuals with a sibling with a disability, that individual may experience disruptions to their psychological well-being due to disequilibrium in one or more dyads within the system. These studies highlight the multiplicative effect of raising multiple children with disabilities, underscoring the need for targeted psychosocial resources.

METHODS

Mauritius, a small island nation in the Indian Ocean with a population of approximately 1.3 million, has an estimated 59,870 persons living with disabilities, equating to nearly 1 in 22 people (Statistics Mauritius, 2015). Due to limited data on parents raising a member with Down syndrome in Mauritius, purposful sampling was used to select sixteen (16) Mauritian parents (aged 40-66) deemed information-rich for this

qualitative study, representing the primary caregiver of young adults with Down syndrome, including twins. Participants are married with multiple children, except one widow, and their young adults with Down Syndrome (9 boys, 5 girls, including one set of twins) ranged from 13 to 40 years old. According to literature, the minimum sample size to achieve saturation in qualitative data analysis is at least 12 respondents (Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper, H. L., & Shelton, R. C. 2019; Braun, V., & Clarke, V. 2019) and this research caters for 16 respondents. Recruitment was effected through one NGO 'U-Link and Down Syndrome Mauritius', serving individuals with Down syndrome in Mauritius. Using an interpretive phenomenological approach guided by Van Manen's (2016) methodology, the study explored parents' lived experiences and strengths despite the emotional challenges they face. One of the research objectives is to see how the Mauritian parents construct meaning in raising twins and young adult with DS and rely on rich, contextually grounded interpretations of narrative experiences, uncovering layers of meaning with essential characteristics of strengths and challenges within broader societal and cultural significances (Lim, W.M. 2024).

Data Collection and Interview Process

Given the lack of accurate statistics on the number of people with DS in Mauritius, a purposeful sampling approach was employed. Parents are chosen as the primary respondents for this study because of the closeness and personal contact with their young adult's needs, challenges and strengths. Semi-structured interviews were conducted during two periods: October–December 2020 and October–November 2024. Parents were asked to describe their experiences, feelings, thoughts and coping mechanisms related to being parent of a young adult with Down syndrome. In period one, parents from social contacts were selected at the first wave for interview. During this phase, it was observed that there was a lack of openness from parents' on their experiences and the researcher could only gather basic, uncover simple themes, behaviours and little valuable information that correspond to the depth of this study. According to study of Lim, W.M (2024), exploring complex phenomena within human-centred contexts, it is important to delve into the contextual relevance, in-depth insights, holistic perspective literature and actively seeks out the lived experiences and perspectives of parental coping styles in different phases. It felt that more meetings with the same participants became necessary to develop this research with rich, precise, contextually relevant themes and capture critical insights and then decided to retake the study after some time. In the light of this, the second wave was organised and it became more interesting and comprehensive to see how the experiences have changed over time and over their lifecourse. When comparing the second wave to the first wave, a pertinent point was noticed about the parental behaviours and genuine connection of diluting the complexities into a more exposed and well-told experiences and was likely winning their hearts for more clarity about the paradoxical parenting and feelings. In the second wave, parents highlighted having frequent meetings with NGOs and socialise with other parents in the same condition and this further enlightened my study and strengthened the course of actions towards parental resilience. In a disguised way, these two-phase techniques acted as a natural stepping stones that has allowed to enhance the research process, foster a holistic understanding of the complex phenomena of paradoxical parenting, leading to richer insights and more nuanced conclusions. Gathering face-to-face interviews were conducted mostly at participants' homes, lasting approximately two hours each, with follow-up phone interviews in period two for clarification. Interviews were audio-recorded and transcribed verbatim. Contextual notes were made after each interview to enrich data interpretation. The interview process followed an interview guide with the lists of questions to be asked and this help to maximise consistency of data collection in both periods. The interview guide included open-ended questions about parenting roles,

family dynamics, child development, coping mechanisms, social support, and parental well-being. Participants were encouraged to freely share their stories, providing control over the meaning-making process, rather than focusing narrowly on stress or grief. The conduct of interviews reached thematic saturation in the second phase. All participants provided informed consent after receiving explanations about the study’s purpose, confidentiality, and voluntary participation. The NGOs provided formal consent to carry out this study. Anonymous code was applied to streamline the thematic analysis of each participant as shown in the table below of ‘participant characteristics’. For illiterate participants, consent was obtained from legally authorized representatives. The research followed ethical protocols allowing participants to withdraw at any time.

Data Analysis

Data analysis followed by Clarke, V., & Braun’s. V. (2013) thematic analysis framework, supported by Atlas.ti software. The researcher familiarized herself with the transcripts by repeated reading and note-taking to identify patterns. A systematic coding process was employed in an inductive approach as displayed in tables below. Codes were grouped into themes and subthemes from both waves, reflecting parental experiences and coping strategies. Themes were refined through collaborative review with independent experts to enhance rigor and minimize bias. Saturation was reached when no new codes or themes emerged. The collection of data run over two phases was effective as it allowed to go back and examined other themes, drew out patterns and followed transitions across the four-tiered perspectives: Child, Parents, Family and Community. This was highly effective and useful when exploring and evaluating new and under-researched phenomenon in the local context on in-depth parental experiences and derive their unique life contexts.

FINDINGS AND DISCUSSION

Participants ranged the age from 40 to 66 years old, with various educational backgrounds from primary to master’s degrees and represent matured parenting with clearer perspective to raising children of older age with Down syndrome. Most mothers were housewives, while fathers were employed in public or private sectors. The young adults with Down syndrome ranged from 13 to 40 years old, including a set of twins (see Table 1).

Table 1: Participant Characteristics

S/N	Parent	Age	Profession	Marital Status	Education	No. of children	DS Age	Gender	Code
1.	Mother	66	Retired	Widow	Primary	4	Twins 30	F	001
2	Mother	51	Housewife	Married	Secondary	2	17	F	002
3.	Mother	40	Housewife	Married	Primary	2	16	M	003
4.	Mother	63	Retired	Married	Primary	1	39	M	004
5.	Father	62	Private employee	Married	Master degree	2	30	M	005
6	Mother	57	Housewife	Married	Secondary	2	27	F	006
7	Mother	55	Housewife	Married	Secondary	3	30	F	007
8	Mother	54	Housewife	Married	Secondary	2	22	M	008
9	Mother	58	Public employee	Married	Bachelor degree	2	25	M	009
10	Father	56	Public employee	Married	Primary	5	15	M	010

11	Mother	53	Housewife	Married	Primary	3	19	F	011
12	Father	58	Self-employed	Married	Secondary	2	23	M	012
13	Mother	42	Private employee	Married	Secondary	2	13	F	013
14	Father	55	Public employee	Married	Secondary	2	18	M	014
15	Mother	56	Unemployed	Married	Primary	2	32	M	015
16	Mother	51	Unemployed	Married	Secondary	2	17	M	016

This study’s thematic analysis revealed rich, nuanced insights into the paradoxical experiences of parents raising young adult and twins with Down syndrome in Mauritius. The findings (in the tables below) crystallize into two overarching dimensions positive and negative each interacting across child, parent, family, and community levels, consistent with Family Systems Theory (Turnbull, A. P., & Turnbull, H. R. 1990). (see table 2)

Table 2: Generic Emerging Thoughts on Negative and Positive dimensions

Negative dimensions	Positive dimensions
Chronic stress, stressful experiences	Happy, good quality of life
Daily care demands	Strong positive feelings
Emotional distress, emotional stress	Parents lives have increased meaning
Maternal depression	Enrichment as a result of their experience
Interpersonal difficulties	Claims of personal growth
Parental discord	Positive views about relative with a disability
Financial problems, extra financial burdens	Positive perceptions
Adverse social consequences	Adapt in a manner that restores faith in the goodness and inherent value of self and of live
Social isolation	Growth and development of the self and the family unit
Marital conflicts, marital dissatisfaction, higher risks of marital discord	Mother’s personality
Fatigue, burnout, anxiety, stigma, strain	Religious support
Loss of leisure time due to care-taking responsibilities	Optimism
Negative reactions from others	Positive attitude
Every day management of disruptive behaviours	Social support from family, parents, friends and community
Heavy caregiving responsibilities	Spirituality, Faith in God
Concerns about the future of the child – Parents are no longer able to care for him/her	Positive outlook on the part of supporting parents
Deleterious effects, traumatic event	More compassionate
Feelings of pessimism, hostility and shame, embarrassment	Less self-focused

Denial, projection of blame, guilt, constant grief, withdrawal, rejection	Developing endurance
Helplessness, feelings of inadequacy, anger, shock and guilt	Greater personal strength
Disbelief, depression and self-blame	Facing life with new boldness
Tragedy, better dead than disabled	Cultivate a sense of humor
Negative and unrealistic	Increase the 'happy times' in life
Fatalistic attitudes	Positive outlook
External dependence in families	Hope, growth
Could not do anything and just needed help and sympathy	Commitment and patience
Low motivation	Tolerance & resilience
A punishment for past karmas, a curse, sins committed	Gratitude
Harmful psychological effects	Strong Relationship
Negative health outcomes	Accepting responsibility
Unstable emotionality,	Venting emotions
Psychological ill health, unsatisfactory social health	Acceptance
Low self-efficacy	Household income
Significant demands	Parenting efficacy

The above emerging themes were further refined into four layers: Child, Parents, Family and Community and are displayed below in this study. This research showcases the interactions between these different levels and there is ample evidence to suggest that some parents raising young adult with DS reported lower self-efficacy while others reported the fear of the future while dealing with their young's adult challenging behaviours but described their faith in God as a source of hope and strength to cope with their difficulties. (see table 3)

Table 3: Positive Dimensions: Experiencing Joy, Growth, Coping and Resilience

Main Themes Category	Common Themes	Coping Strategies	Main Themes Category	Common Themes	Coping Strategies
Child Level	Child diagnosis with Down syndrome; Child characteristics; Autonomy; Child relative self-support; Child activity level; Routine	Creating a warm relationship with the child; warm welcome; accepting the situation and others; God's will; involving with the "Down Community"; developing autonomy and self-sufficiency;	Parent Level	Parents' reaction; Parents as model; Partner relationship; Parents' resilience and autonomy; Physical/material support; Parent characteristics; Parents' participation; Happy parents; Caring parents;	Avoiding or resolving negative feelings; Expressing feelings and affection; Spiritual growth & support; Family physical activity; Independence; A moment for parent; Familiarizing with child's supportive needs; Acceptance

		providing autonomy support; attention-seeking; social network and professional counsel		Importance to child’s health and conditions; Flexible work conditions; Positive feelings & assistance; DS advantages; Source of hope, aspiration, gratitude, joy & love; Parental expectations; Parental burnout; Mother’s & father’s role	and inclusion; Being more involved in religious activities; Increasing faith or seeking help from God
Family Level	Family members support & relationship; Family functioning & stability; Supportive information gathering to cater for child’s needs; Developing familial support; Siblings as motivators; Social interaction development; Family routine & behaviour; Culture, spirituality & beliefs; Happiness and togetherness; Communication, comprehension and collaboration	Increasing adaptability; Increasing togetherness & cohesion; Developing parents’ information support sources (doctors and other professionals); Accompanying the child in social interactions; Family religious beliefs; Belief in divine providence; Worship to obtain peace; Increased religious involvement; Increasing faith or seeking help from God; Respect and empowerment with moral values	Community Level	Family reactions; Clustering with NGOs; Network with DS community; Caring family; Access to other institutions; Regular social networking (online or offline); Presence of social support systems; Peer support; Communication; Proximity of resources; Access to services; State and local community support and services; Access to inclusive facilities; Access to early intervention, medical specialists & related professionals; Law protection	Keeping active in activities/hobbies; Social inclusion; Seeking assistance and support from others; Teaching/advising other individuals how to interact with the child in public areas; Freedom of thought, movement, decision-making, and self-care

Child Level:

From the accounts, parents celebrated their children's distinct personalities and milestones, emphasizing moments of joy and increasing autonomy. Parents narrated that their children's autonomy help them to grow and it corroborates the findings of Ijezie, O.A., Healy, J., Davies, P., Balaguer-Ballester, E., & Heaslip, V. (2023), by showing the value and importance of becoming independent, participating in the communities, knowing their human rights and the key role parents play in raising them. These sentiments echo findings of Skotko, B. G., Levine, S. P., & Goldstein, R. (2016) and Barklı, A., & Doğan, A. (2025), that emphasize the role of positive affectivity and benefit-finding in parental well-being. From the findings, the families experienced a transformative process from which they learn to tolerate, accept and finally celebrate the birth of their own child. The parents' narratives show alignment with the "Down Syndrome advantage" hypothesis, which suggests lower parental stress and higher familial support and cohesion compared to other disabilities, linked to adaptive child behaviors and supportive family dynamics (Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. 2024; Sheldon, J.P, Oliver, M. & Yashar, B.M. 2021; Mitchell, D.B., Hauser-Cram, P., & Crossman, M.K. 2015). The 'DS advantage' indicates that parents having a child with DS, enjoy greater parenting rewards compared to parents raising other types of developing disabilities because of behavioural phenotype, less severe problem behaviours, easy-going temperament, cheerful, outgoing and apparently positive personality traits and characteristics of children themselves (Channell, M.M., McDuffie, A.S., Bullard, L.M., Abbeduto, L. 2015; Adamson, L.B., Deckner, D.F., Bakeman, R. 2010; Fidler, D.J, Most, D.E, Booth-LaForce C., & Kelly, J.F. 2008) . From the findings, parents confer an advantage with more social support thus making their parenting experience less stressful but with more positive interactions.

One mother reflected:

"They are gifts from God. Watching the girls learn to communicate and engage with others fills my heart every day. Their smiles light up the family." (Code 001)

Another parent highlighted how her child's progress inspired hope:

"He surprised me when he started going to the community center. He is not just my son with Down syndrome; he is growing into a young man who wants to be independent." (Code 003)

Parent Level:

From the accounts, faith and spiritual coping were key strategies in managing emotional distress, resilience and gradually rebuilding hope amidst emotional hardship and other challenges. Parents find strength during difficult experiences and thus turn to prayer, acceptance and trust in God's plan to face fear, guilt and hopelessness stemming from social support (Lakhani, A., Ali, T.S., Kramer-Roy, D., & Ashraf, D. 2024; Findling, Y., Barnoy, S. & Itzhaki, M. 2023). This "can-do" mindset was a recurrent theme, reflecting positive reappraisal and meaning-making strategies central to coping models. The frequent invocation of faith and spirituality resonates with the cultural context of Mauritius and the documented role of religion and informal social support (Lakhani, A., Ali, T.S., Ashraf, D., & Roy, D.K. 2025; Çaksen, H. 2025) in buffering stress among parents of young people with disabilities. Parents described an evolving identity characterized by resilience, advocacy, and spiritual growth. As one father stated:

"Initially, I was overwhelmed. But over time, I learned to be an advocate for my son. Our faith in God gave me strength to face daily challenges." (Code 005)

Family Level:

From the encounters, supportive family interactions and sibling encouragement were pivotal and reshaped the entire family dynamic and enhanced cohesion with the theory

of Family Systems Theory. From the studies of (Alon, R. 2026; Skotko, B.G. & Levine, S.P. 2006), the support of siblings build optimism, acceptance and nurture sibling relationships and future caregiving. Sibling involvement not only benefits the child with special needs but also fosters empathy and social learning within the family unit (Steed, L. C., & Langlais, M. 2025).

One mother shared:

"Our other children love and protect their siblings with Down syndrome. The family has grown closer; we communicate more and support each other." (Code 007)

Community Level:

Parents valued connections with Down Syndrome organization as their own community and involved in inclusive community activities. The holistic support systems for individuals with DS in Saudi Arabia and engagement in peer support group play a crucial role in enhancing their quality of life (Praveen, S. Ahmad, A. and Reshi, A.A. 2024) and offer emotional sustenance in line with the theory of FST. The respondents claimed that community-based programs and other activities in NGOs are essential to help families understand DS and to empower the kids with DS into the community with adequate resources, promoting inclusion, sense of belonging and social interaction. The Mauritian families will be better equipped to provide the best possible care and advocacy for their loved ones and surroundings as depicted in theory. But, the extent of community inclusion varied, often limited by infrastructural and societal barriers. Nevertheless, active advocacy efforts demonstrate parental agency, consistent with research emphasizing empowerment in disability contexts (Farkas, L. et al 2019). One of the participants stated that his child cannot keep up with schooling but is grateful for the NGO that allow him to experience inclusion and provide endlessly support in this learning growth in a different way but look further for respite care.

One participant noted:

"Joining the Down Syndrome Association changed everything. I no longer feel alone. We share stories, strategies, and hope." (Code 002)

The Twin Experience

Parents of twins with Down syndrome emphasized both the amplified caregiving demands and deep blessings. From studies of Lambert, F. (2003) and Niedbalski, J. (2025), a parent of twins with intellectual disabilities is extremely challenging, caregiving intensifies stress and requires extra work but it is noticed that the positive side of 'twin-thing' is that they are at the same level, mutually supportive and this strengthens adaptive family coping. The rarity of identical twins with DS compounded public curiosity and emotional intensity, but also reinforced family bonds and collective purpose. Under the Family Systems Theory, a family is perceived as an interconnected emotional unit. As such, the diagnosis, health needs, and developmental milestones of twins with DS cause a domino effect throughout the entire family system. A mother poignantly accounted that this was a phenomenal shock but acknowledged of doing everything in her power in an extremely organised way to help the identical girl twins to get all those things that one wants from one's children. She added:

"Caring for the girls means double the work but double the love. They are miracles; their smiles erase the fatigue" (Code 001). (see table 4)

Table 4: Negative Dimensions: Grappling with Stress, Stigma, and Structural Barriers

Main Themes Category	Common Themes	Coping Strategies	Main Themes Category	Common Themes	Coping Strategies
Child Level	Diagnosis with DS – unpreparedness to the child’s condition & impact of disability; DS diagnosis; Dependence; Physical needs; Need for company; Assistive devices; Severe health condition; Isolation; Peer reaction; Physical demands and child’s needs; Insufficient development; Limitations in self-care; Communication & language problems; High temperament; Disruptive behaviour; Stigmatization/social stigma; Problematic behaviours	Adaptive behaviour; Socialization; Connecting	Parent Level	Unreadiness to child’s condition; Shock; Denial; Guilt; Negative feelings; Rejection; Lack of knowledge & skills to care for a child with disability; Parental stress; Emotional exhaustion; Marital conflicts; Burnout; Work responsibilities; Parental burden; Marital tensions; Grief; Fear of the unknown; Future expectancy; Limited time; Looking after other children; Frustration; Financial burden; Stigmatization and attitudes of others; Blurred future; Over-parenting	Knowledge and skills for parents; Adjustment & adaptation; Marital support/status
Family Level	Family instability; Insufficient funds for treatment, extra care, and other needs; Lack of harmony and support; Misunderstanding; Lack of communication; Loaded responsibilities; Lack of support from family members	Greater participation of family members; Increased family involvement in caring for the child with DS; Maintaining routines	Community Level	Absence of social support; Restricted mobility; Limited access to facilities and services; Impact on social life; Limited access to education and other facilities; Structural and process barriers; Limited access to public areas and transport; Seeking more information; Socio-cultural implications;	More support; Removal of barriers; Fostering an inclusive mindset; Mobility access policies in different areas; Strengthening legal protection for people with disabilities; Policy improvements

Child-Level Challenges:

The initial diagnosis was overwhelmingly distressing, triggering shock, denial and grief. Parents struggled with behavioral challenges, communication difficulties, and medical complications. Isolation, both social and emotional, was frequently reported.

The narrated statements are:

"When the doctor said 'your son has Down Syndrome,' my world collapsed. I felt lost, afraid of what the future holds." (Code 012)

"People avoid us; they don't understand. My child is treated differently at school and in the community." (Code 008)

These experiences resonate with the studies of (Er-rida S, Oubibi M, Mafhoum M, Alami M, Alaoui A. 2025; Runcheva, J., Perić Prkosovački, B., & Stojanovska, S. 2025), documentation of parental grief, lack of adaptive educational strategies and social exclusion, exacerbated by cultural misconceptions and where disability is sometimes seen as a spiritual failing (Chitando, & Ohajunwa & Dube, K., 2025; Ndlovu, H.L. 2016).

Parental-Level Struggles:

Participants expressed emotional exhaustion, guilt, frustration, and marital tensions. Balancing caregiving with employment and care of other children often led to burnout. Parents manifested on the financial strain and uncertainty about their children's long-term care were persistent stressors. The statements from parents confessed:

"Sometimes I feel overwhelmed. I want to do everything perfectly but end up exhausted and guilty." (Code 006)

"Who will care for him when we are gone? The future is scary." (Code 014)

These concerns of uncertainty mirrored the findings of Bujnowska, A.M., Rodríguez, C., García, T., Areces, D., & Marsh, N.V. (2019) and Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. (2025) on the spillover effects of caregiving stress on family wellbeing and the fear about the lack of kindness and empathy in the world that may affect their children and show future anxiety about who will be there to protect them in the absence of parents.

Family-Level Instability:

Cultivating a robust support system from family members is pivotal as highlighted in FST theory and this encompasses support from spouses, children, extended family members, relatives and other stakeholders in the community surroundings. The demands of caring for a member with DS impact the family relationships and according to Bhandari, C., Douglas, S.N., Jensen, E.J. & West, P. (2025) impact siblings and marriage relationships and put on huge strain on their relationship and the entire family system. Strained communication, uneven caregiving roles, and lack of extended family support challenged family harmony. One participant noted:

"My in-laws don't understand. I carry most of the burden, and it is lonely." (Code 002)

This underscores the fragility of social and family support in some families and the risk to family cohesion documented in previous studies (Darla, S., & Bhat, D. 2021).

Community-Level Barriers:

Parents described limited access to inclusive education, inadequate resources, healthcare, and assistive technologies. This was consistent with Boot, F.H., MacLachlan,

M., & Dinsmore, J. (2020) on factors influencing access and continued use of assistive products for people with intellectual disabilities living in group homes. Painted from literature, raising a child with a disability as an unmitigated tragedy for the entire family but these narratives have shifted into growing open-mindedness with the help of disability rights and legal support. Legal protections, cultural adaptation and disability awareness were noted as insufficient, echoing regional research on infrastructural gaps and resource-related barriers (Nimusiima et al., 2024; Parveen, S. Ahmad, A. and Reshi, A.A. 2024; Abebe, S. M., Batorowicz, B., Xu, X., Okoroafor, N. A. E., Mekonnen, F., Melak, M. F., & Aldersey, H. M. 2023). Social stigma manifested in public spaces and schools, increasing isolation. A focus on social construction of disability could help to address parental caretaking hardships without stigmatizing people with disabilities.

"There are no ramps, no special schools nearby. Society doesn't accommodate my child." (Code 006)

Synthesis: The Parenting Paradox in Context

The duality of joy and hardship reflects the parenting paradox, where love and pride cohabit with stress and uncertainty. Parents' narratives demonstrate dynamic coping shaped by cultural context, spiritual beliefs, family interactions, and community support. These findings support the transactional view of family adaptation (Kerig, P. K. 2019; Yakren, S. 2018) highlighting reciprocal influences between individuals and their environments. It looks like the paradoxical feelings appear as a profound failure for parents to accept and love their children fully because of disability, but in fact, serve as an important coping mechanism and driving force behind difficult caretaking work.

Parents who accessed community resources and nurtured supportive family environments exhibited greater resilience, confirming the buffering role of social capital (Albedeiwi, M.S., Alshammari, S.N. & Aluzeib, A.A., 2022; Souza, M.S., Romano, M.C.C., Oliveira, P.P., Duarte, E.D., & Braga, P.P. 2024). The inclusion of twins with Down Syndrome adds depth to the literature, revealing how multiplicity intensifies caregiving demands but also fosters solidarity and meaning.

CONCLUSION

This study illuminates the complex and multifaceted lived experiences of Mauritian parents raising adult and twins with Down syndrome, revealing a profound parenting paradox characterized by simultaneous joy and struggle, resilience and vulnerability. Anchored in Family Systems Theory, the research highlights how emotional responses evolve from initial shock and grief to acceptance, spiritual reframing, and advocacy. Parents' narratives underscore the vital roles of family cohesion, community support, and cultural beliefs in shaping adaptive coping and resilience. Parents experiences not only grief and despair, but also love and joy, even in the most extreme circumstances, such as, when their child is unresponsive due to multiple severe health conditions and disabilities. The inclusion of a rare case of identical twins with Down syndrome adds a unique perspective, demonstrating intensified caregiving demands balanced by enhanced familial solidarity and meaning-making. Despite positive dimensions such as strengthened bonds and personal growth, parents continue to face significant challenges, including stigma, limited access to inclusive services, financial strain, and emotional fatigue.

These findings contribute to a more balanced understanding of parenting adult with Down syndrome, moving beyond deficit-focused models to recognize both the transformative potential and persistent systemic barriers in resource-constrained, culturally diverse settings like Mauritius. This study underscores the need for culturally

sensitive, multidimensional support systems that acknowledge the parenting paradox, promote inclusion, empowerment, and sustainable family well-being.

It is recommended that stakeholders have to contribute towards family-centered psychosocial counselling, peer support programs and promote collaboration across the state, healthcare, education and community sectors to coordinate effective and comprehensive family support. Other bodies such as the Ministry of Social Security, National Empowerment Foundation and other religious bodies, leaders and media organization may launch culturally sensitive awareness campaigns to reduce stigma. Advocacies to implement inclusive education policies with appropriate resources with the relevant ministries will help the young individual with Down syndrome. Healthcare service is a vital support that need to be strengthened by the Ministry of Health and Wellness, public hospitals, pediatric specialists, therapists (speech, occupational) and other professionals through multidisciplinary teams focused on early intervention and ongoing support.

Limitations and Future Research

There are few caveats presented in this study. With inadequate data on the number of individuals with Down syndrome in Mauritius, the findings arise from a small sample size. Although it is sufficient to achieve saturation in the analysis, it is relatively small. Studying old parents with older children with DS, excluding single parents, are highlighted and therefore, conclusions cannot be generalised on a broader analytical categories. Another caveat is that this research was conducted in Mauritius. Given the qualitative nature of this research and the specificity of Mauritian's social-cultural context, the outcomes of this study cannot be extrapolated. Further exploration of themes and the selection of interviewees to include other young age categories of parents are call for future research. Although this study was guided by the principles of Family Systems Thoery, the exploration of multiples and indepth themes, encompassing the four levels (child, Parents, Family and Community), warrant solid grounds for generating broader arguments to contribute to the emergence of a model or theoretical concept as future research. Further research should incorporate multiple stakeholders to develop a more comprehensive understanding of support mechanisms and policy implementation for families navigating special needs caregiving.

Funding: Not applicable.

Conflicts of interest: The authors declare that they have no competing interests.

Ethical Approval: The study was supported by the Open University of Mauritius Research Committee and no ethical issues were raised on the approved research proposal.

Consent to Participate: Informed consent was obtained from all individual participants included in the study. Participants were advised that they were free to withdraw at any time, should they wish to do so. The NGO provided consent to conduct this study with its members.

Consent to Participate: The authors provide consent for this article to be published.

Data Availability Statement: The in-depth contributions presented in the study are included in the article. The data supporting the findings will be made available by the authors on request.

Credit Authorship Contribution: All authors contributed equally in the conceptualization, investigation, methodology and writing.

Acknowledgements: Sincere thanks are extended to the NGO and all parents who participated in this study.

REFERENCES

1. Abebe, S. M., Batorowicz, B., Xu, X., Okoroafor, N. A. E., Mekonnen, F., Melak, M. F., & Aldersey, H. M. (2023). Understanding Barriers and Facilitators to Inclusive Education for Grade 7-9 Students with Disabilities in Ethiopia and Ghana: A Qualitative study. *Disability, CBR & Inclusive Development*, 34(1), 6-26.
2. Adamson, L.B., Deckner, D.F., Bakeman, R. (2010). Early interests and joint engagement in typical development, autism, and Down syndrome. *Journal of Autism and Developmental Disorders*. 2010;40:665–76. doi: 10.1007/s10803-009-0914-1. [DOI] [PMC free article] [PubMed] [Google Scholar]
3. Albedeiwi, M.S., Alshammari, S.N. & Aluzeib, A.A. (2022). Emotional Burden and Copying Styles in Parents of Children with Down Syndrome. *Journal of University Studies for Inclusive Research*. Vol. 8, Issue 7 (2022), 3812-3837, USRIJ Pvt Ltd
4. Alon, R. (2026). How do typically developing brothers and sisters accept their siblings with Down syndrome or autism? An examination of personal characteristics. *Autism*, 30(1), 84-96.
5. Alsamiri, Y.A. Alaghdaif, A.A. Alsawalem, I.M. Allouash, B.A. & Alfaidi, S.D. (2024). Mothers of children with disabilities: exploring lived experiences, challenges and divorce risk. *Frontiers in Psychology*. 15:1399419. doi: 10.3389/fpsyg.2024.1399419
6. Alshdaifat, S. (2025). The Jordanian Rights of Persons with Disabilities Law of 2017: How is Disability Addressed? A Policy Analysis. *Journal of Legal Sciences*, 40(1), 540-582.
7. Barklı, A., & Doğan, A. (2025). Raising a Child with Autism Spectrum Disorder: Examining Parental Factors. *Psikiyatride Güncel Yaklaşımlar*, 17(2), 197-210.
8. Bhandari, C., Douglas, S.N., Jensen, E.J. & West, P. (2025). Stress and Coping among Family Caregivers of Children with Down Syndrome: a Meta-synthesis of Qualitative Research. *Rev J Autism Dev Disord*. <https://doi.org/10.1007/s40489-025-00534-w>
9. Boot, F. H., MacLachlan, M., & Dinsmore, J. (2020). Are there differences in factors influencing access and continued use of assistive products for people with intellectual disabilities living in group homes? *Disability and Rehabilitation: Assistive Technology*.
10. Bornstein, M.H. (Ed.). (2019). *Handbook of Parenting: Volume 3: Being and Becoming a Parent, Third Edition (3rd ed.)*. Routledge. <https://doi.org/10.4324/9780429433214>
11. Bottcher, L & Dammeyer, J. (2025). Parents' Strategies for Taking Care of Their Child with Disability: The Challenges of Being Parents of a Child with Cerebral Palsy in the Danish Social Welfare System. *Scandinavian Journal of Disability Research (SjDR)*. Vol.27 (1):1-14, <https://doi.org/10.16993/sjdr.1154>
12. Braun, V., & Clarke, V. (2019). To saturate or not to saturate? Questioning data saturation as a useful concept for thematic analysis and sample-size rationales. *Qual. Res. Sport Exerc. Health* 13, 201–216. doi: 10.1080/2159676X.2019.1704846
13. Brown, G. (2022). Adorable twins with Down syndrome are 1(or rather, 2) in a million. *Today*. <https://www.today.com/parents/babies/adorable-twins-syndrome-are-1-million-rcna13522>
14. Bujnowska, A.M., Rodríguez, C., García, T., Areces, D., & Marsh, N.V. (2019). Parenting and Future Anxiety: The Impact of Having a Child with Developmental Disabilities. *Int J Environ Res Public Health*. 2019 Feb 25;16(4):668. doi: 10.3390/ijerph16040668.
15. Çaksen, H. (2025). Religious coping in parents of children with Down Syndrome: a systematic review of the literature. *Journal of religion and health*, 64(1), 462-518.
16. Centers for Disease Control and Prevention. (2019). Facts about Down Syndrome. Atlanta, GA: CDC.
17. Celik, P., & Kara Uzun, A. (2023). Stressful experiences and coping strategies of parents of young children with Down syndrome: A qualitative study. *J Appl Res Intellect Disabil*. 36(4):881-894. doi: 10.1111/jar.13108.
18. Chaudhry, N., Sattar, R., Kiran, T., Wan, M.W., Husain, M., Hidayatullah, S., Ali, B., Shafique, N., Suhag, Z., Saeed, Q., Maqbool, S. & Husain, N. (2023). Supporting Depressed Mothers of Young Children with Intellectual Disability: Feasibility of an Integrated Parenting Intervention in a Low-Income Setting. *Children*, 10, 913. <https://doi.org/10.3390/children10060913>.
19. Channell MM, McDuffie AS, Bullard LM, Abbeduto L. (2015). Narrative language competence in children and adolescents with Down syndrome. *Front Behav Neurosci*. doi: 10.3389/fnbeh.2015.00283. PMID: 26578913; PMCID: PMC4626566.
20. Chitando, E., & Ohajunwa, C. & Dube, K. (2025). Introduction: Religion, disability and sustainable development in Africa. In *Religion, Disability, and Sustainable Development in Africa (pp. 1-18)*. Routledge.

21. Clarke, V., & Braun, V. (2013). Teaching thematic analysis: Overcoming challenges and developing strategies for effective learning. *The Psychologist*, 26(2), 120–123
22. Cunningham, C. (1996) Families of children with Down syndrome. *Down Syndrome Research and Practice*, 4(3), 87-95. doi:10.3104/perspectives.66
23. Darla, S., & Bhat, D. (2021). Health-related quality of life and coping strategies among families with Down Syndrome children in South India. *Medical journal armed forces india*, 77(2), 187-193. <https://doi.org/10.1016/j.mjafi.2020.07.010>
24. Davies, A., Rix, J. & Robb, M., (2024). "Fathers' Relationships with Their Disabled Children: A Literature Review", *Disability Studies Quarterly* 43(3). doi: <https://doi.org/10.18061/dsq.v43i3.8744>
25. Desimpelaere, E.N., De Clercq, L.E., Soenens, B., Prinzie, P. & De Pauw, S.S.W. (2023). Parenting a child with Down syndrome: A qualitative study on parents' experiences and behaviours from a self-determination theory perspective. *Journal of Pediatric Nursing*. Elsevier Inc. <https://doi.org/10.1016/j.pedn.2023.10.021>
26. Er-rida S, Oubibi M, Mafhoum M, Alami M, Alaoui A. (2025). Challenges Faced by Parents of Children with Down Syndrome in Mainstream Schools: Exploring Inclusive Education. *Open Psychol J*, 2025; 18: e18743501360190. <http://dx.doi.org/10.2174/0118743501360190250101113909>
27. Farkas, L., Cless, J. D., Cless, A. W., Nelson Goff, B. S., Bodine, E., & Edelman, A. (2019). The ups and downs of Down Syndrome: A qualitative study of positive and negative parenting experiences. *Journal of Family Issues*, 40(4), 518-539. <https://doi.org/10.1177/0192513X18812192>
28. Fidler, D.J, Most, D.E, Booth-LaForce C., & Kelly J.F. (2008). Emerging social strengths in young children with Down syndrome. *Infants and Young Children*. 2008;21:207–20. doi: 10.1097/01.IYC.0000324550.39446.1f.
29. Findling, Y., Barnoy, S. & Itzhaki, M. (2023). "God gave you a special child because you are special": difficulties, coping strategies, and parental burnout of Jewish mothers – a qualitative study. *Front. Psychol.* 14:1259670. doi: 10.3389/fpsyg.2023.1259670
30. Galán-Vera, I. Z., Robles-Bello, M. A., Sarhani-Robles, A., & Valencia-Naranjo, N. (2025). Experiences and coping strategies of parents with children diagnosed with autism spectrum disorder in early care with emphasis on social skills and family cultural values: A qualitative study. *Archives of Psychiatric Nursing*, 56, 151864.
31. Gothwal, V.K., Bharani, S., & Reddy, S.P. (2015) Measuring Coping in Parents of Children with Disabilities: A Rasch Model Approach. *PLoS ONE* 10(3): e0118189. <https://doi.org/10.1371/journal.pone.0118189>
32. Grech, S. (2016). Disability and development: Critical connections, gaps and contradictions. In *Disability in the global South: The critical handbook* (pp. 3-19). Cham: Springer International Publishing.
33. Hendrix, J.A, Amon, A., Abbeduto, L., Agiovlasitis, S., Alsaied, T., Anderson, H.A., Bain, L.J., Baumer, N., Bhattacharyya, A., Bogunovic, D., Botteron, K.N., Capone, G., Chandan, P., Chase, I., Chicoine, B., Cieuta-Walti, C., DeRuisseau, L.R., Durand, S., Esbensen, A., Fortea, J., Giménez, S., Granholm, A.C., Hahn, L.J., Head, E., Hillerstrom, H., Jacola, L.M., Janicki, M.P., Jasien, J.M., Kame,r A.R., Kent, R.D., Khor, B., Lawrence, J.B., Lemonnier, C., Lewanda, A.F., Mobley, W., Moore, P.E., Nelson, L.P., Oreskovic, N.M., Osorio, R.S., Patterson, D., Rasmussen, S.A., Reeves, R.H., Roizen, N., Santoro, S., Sherman, .SL., Talib, N., Tapia, I.E., Walsh, K.M., Warren, S.F., White, A.N., Wong, G.W., & Yi, J.S. (2021). Opportunities, barriers, and recommendations in down syndrome research. *Transl Sci Rare Dis.* 5(3-4):99-129. doi: 10.3233/trd-200090.
34. Ijezie, O.A, Healy, J., Davies, P., Balaguer-Ballester, E., & Heaslip, V., (2024). Quality of life in adults with Down syndrome: A mixed methods systematic review. *PLoS One.* 2023 May 1;18(5):e0280014. doi: 10.1371/journal.pone.0280014. *Erratum in: PLoS One.* 3;19(12):e0315110. doi: 10.1371/journal.pone.0315110.
35. Ipsen, C., & Repke, M. (2022). Reaching people with disabilities to learn about their experiences of social connection and loneliness. *Disability and health journal*, 15(1), 101220.
36. Kegler, M. C., Raskind, I. G., Comeau, D. L., Griffith, D. M., Cooper, H. L., and Shelton, R. C. (2019). Study design and use of inquiry frameworks in qualitative research. *Health Educ. Behav.* 46, 24–31. doi: 10.1177/10901981187950
37. Kerig, P. K. (2019). Parenting and family systems. *Handbook of parenting*, 3-35. <https://doi.org/10.4324/9780429433214>
38. Lakhani, A., Ali, T. S., Ashraf, D., & Roy, D. K. (2025). Exploring informal social support experiences and coping strategies in families raising a child with an intellectual disability. *The Family Journal*, 33(1), 150-171.
39. Lakhani, A., Ali, T.S., Kramer-Roy, D., Ashraf, D. (2024). Informal social support for families with children with an intellectual disability in Karachi, Pakistan: A qualitative exploratory study design. *Heliyon.* 2024 Oct 10;10(20):e39221. doi: 10.1016/j.heliyon.2024.e39221.
40. Lambert, F. (2003). Twins with Down syndrome - our experiences. *Down Syndrome News and Update*, 3(1), 8-10. doi:10.3104/dsupdate.206

41. Langley, E. (2025). Father Involvement in the Lives of Their Children With Intellectual and Developmental Disabilities in the UK. *J Appl Res Intellect Disabil*. 38(4):e70091. doi: 10.1111/jar.70091.
42. Lecomte, U., de Los Ríos Berjillos, A., Lethielleux, L., Deroy, X., & Thenot. M. (2024). Social Understanding of Disability: Determinants and Levers for Action. *Behav Sci (Basel)*. 14(9):733. doi: 10.3390/bs14090733.
43. Lim, W.M. (2024). What is Qualitative Research? An Overview and Guidelines. *Australasian Marketing Journal*. Research Toolkit: Foundational Approaches. Vol. 33(2) 199-229.
44. Luetke Lanfer, H., Anderson, E., Bah, F., Krawiec, S., Rossmann, C., & Vines, A. (2025). Experiences of stigma among caregivers of children with disabilities in Freetown. *Scientific Reports*, 15(1), 20236.
45. Mitchell, D.B., Hauser-Cram P., & Crossman, M.K., (2015). Relationship dimensions of the 'Down syndrome advantage'. *J Intellect Disabil Res*. 2015 Jun;59(6):506-18. doi: 10.1111/jir.12153.
46. Mishra, T.A, Pandey, K., Bishnu Bhujel, B. & Shova Adhikari, S. (2022). Burden of Care among Mothers Having children with Down Syndrome. *Journal of Nepal Health Res. Counc. (JNHRC)* Vol 20(57): 977-82
47. Mishra, S. (2025). The Life of Children with Down Syndrome and Their Family: A Narrative Inquiry. *NPRC Journal of Multidisciplinary Research*, Vol. 2, Issue 4, 65-77. DOI: 10.3126/nprcjr.v2i14.88027
48. Ndlovu, H. L. (2016). African beliefs concerning people with disabilities: Implications for theological education. *Journal of Disability & Religion*, 20(1-2), 29-39
49. Nelson Goff, B. S., Monk, J. K., Malone, J., Staats, N., Tanner, A., & Springer, N. P. (2016). Comparing parents of children with Down syndrome at different life span stages: Parents of children with Down syndrome. *Journal of Marriage and Family*, 78(4), 1131–1148. <https://doi.org/10.1111/jomf.12312>
50. Niedbalski, J. (2025). What is it like to be a twin of a person with profound intellectual and multiple disabilities? *Journal of Intellectual & Developmental Disability*, 50(2), 221–234. <https://doi.org/10.3109/13668250.2024.2419412>
51. Nimusiima, C., Kawesa, E. S., Seeley, J., & Mbazzi, F. B. (2024). Adaptation and validation of the child and family follow-up survey (CFFS) tool to measure participation of children with disabilities in Uganda. *African Journal of Social Work*, 14(1), 20-30.
52. Noroozi, F., Farrar, Z., Gharibi, T., & Gashmard, R. (2024). Family self-support in managing Down Syndrome children: A qualitative study. *The Scientific World Journal*, 2024(1), 9992595.
53. Parveen, S. Ahmad, A. and Reshi, A.A. (2024). Empowering Lives: Navigating the Landscape of Down Syndrome Support in Saudi Arabia. *Journal of Disability Research*. 2024. Vol. 3(3). DOI: 10.57197/JDR-2024-0044
54. Raap, E., Weille, K. L., & Dedding, C. (2024). “I am the mother of the kind of child you dread having”: Experiences of living with chronic sorrow among parents with a disabled child. *Journal of health psychology*, 13591053241292822.
55. Rakap, S., & Vural-Batik, M. (2024). Mitigating the impact of family burden on psychological health in parents of children with special needs: Buffering effects of resilience and social support. *Journal of Applied Research in Intellectual Disabilities*, 37(1), e13179.
56. Runcheva, J., Perić Prkosovački, B., & Stojanovska, S. (2025). Support for Children with Down syndrome in Primary School. *Vospitanie- Journal of Educational Sciences Theory and Practice*, Vol. 20, No. 1. doi: 10.46763/JESPT2520132r.
57. Rusu, P.P. Candel, O.S, Bogdan, I. Ilicius, C, Ursu, A. & Podina, I.R. (2025). Parental
58. Stress and Well-Being: A Meta-analysis. *Clinical Child and Family Psychology Review*
59. 2025 28:255-274. doi.org/10.1007/s10567-025-00515-9
60. Rutter, T.L., Hastings, R.P., Murray, C.A., Enoch, N., Johnson, S., & Stinton, C. (2024). Psychological wellbeing in parents of children with Down syndrome: A systematic review and meta-analysis, *Clinical Psychology Review*, Vol.110, 102426, ISSN 0272-7358, <https://doi.org/10.1016/j.cpr.2024.102426>.
61. Safe, A., Joosten, A., & Molineux, M. (2012). The experiences of mothers of children with autism: Managing multiple roles. *Journal of Intellectual & Developmental Disability*, 37(4), 294–302. <https://doi.org/10.3109/13668250.2012.736614>
62. Sharpley, C. F., Bitsika, V., Efremidis, B. (1997). Influence of gender, parental health, and perceived expertise of assistance upon stress, anxiety, and depression among parents of children with autism. *Journal of Intellectual and Developmental Disability*, 22, 1, 19–28
63. Sheldon, J. P., Oliver, M., & Yashar, B. M. (2021). Rewards and challenges of parenting a child with Down Syndrome: A qualitative study of fathers' perceptions. *Disability and Rehabilitation*, 43(24), 3562-3573
64. Skotko, B.G & Levine, S.P. (2006). What the other children are thinking: Brothers and sisters of persons with Down syndrome. *Am J Med Genet Part C Semin Med Genet* 142C:180–186.
65. Skotko, B.G. Levine, S.P & Goldstein, R. (2011). Having a Son or Daughter with Down Syndrome: Perspectives from Mothers and Fathers. *Am J Med Genet A*. 155A(10): 2335–2347. doi:10.1002/ajmg.a.34293.

66. Skotko, B. G., Levine, S. P., & Goldstein, R. (2016). Family perspectives about Down Syndrome. *American Journal of Medical Genetics Part A*, 170A(4), 930–941. <https://doi.org/10.1002/ajmg.a.37520>
67. Soll, B.A., Oxenham, V., Kowlessur, S., Kassam, F., Bhoosun, O., & Reebye, R. (2025). Perspectives of Mauritian living with neurological disability and their family caregivers during the COVID-19 lockdown: a thematic analysis from an African nation. *Pan Afr Med J*. doi: 10.11604/pamj.2025.52.57.48098
68. Souza, M.S., Romano, M.C.C., Oliveira, P.P., Duarte, E.D., & Braga, P.P. (2024) Family coping in caring for children with Down syndrome: a scoping review. *Rev Rene*; 25:e92092. DOI: 10.15253/2175-6783.20242592092 Statistics Mauritius. (2015). Census of Population and Housing. *Government of Mauritius*.
69. Statistics Mauritius (2026). Beneficiaries of Pensions, April 2026 https://statsmauritius.govmu.org/Documents/Statistics/Monthly/Soc_Sec/2026/Social_M_Apr26_130526.pdf
70. Steed, L. C., & Langlais, M. (2025). Consider the siblings: A mixed-method study on the short-term and long-term consequences of having a sibling with a physical and/or cognitive disability and perceived support. *The Family Journal*, 33(1), 140-149.
71. Turnbull, A. P., & Turnbull, H. R. (1990). A tale about lifestyle changes: Comments on toward a technology of “nonaversive” behavioral support. *The Association for Persons with Severe Handicaps*, 15, 142–144.
72. Turnbull, A. P., & Turnbull, H. R. (2001). Families, Profession-als, and Exceptionality: A Special Partnership. *Columbus,OH: Merrill*
73. Van Manen, M. (2016). Researching lived experience: Human science for an action sensitive pedagogy. *Routledge*.
74. Van Riper, M., (2007). Families of Children with Down Syndrome: Responding to “A Change in Plans” with Resilience. *Journal of Pediatric Nursing*, Vol 22, No 2
75. Van Riper, M., Cosgrove, B., Fleming, L. (2023). Adaptation at the Family Level in Families of Individuals With Down Syndrome: A Scoping Review. *J Fam Nurs*. 2023 Nov;29(4):324-347. doi: 10.1177/10748407231163236.
76. Vilaseca, R., Rivero, M., Ferrer, F., Bersabé, R.M. (2020) Parenting behaviors of mothers and fathers of young children with intellectual disability evaluated in a natural context. *PLoS ONE* 15(10): e0240320. <https://doi.org/10.1371/journal.pone.0240320>
77. Wallis, A., James, K., & Rhodes, P. (2024). Introduction: The Craft and Values of Contemporary Systemic Family Therapy. In *A Practical Guide to Family Therapy* (pp. 1-5). *Routledge*.
78. Woodgate, R.L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qual Health Res*. 2008 Aug;18(8):1075-83. doi: 10.1177/1049732308320112. PMID: 18650563.
79. World Health Organization. Community-based rehabilitation: *CBR guidelines*. Geneva: WHO.
80. Yakren, S. (2018). "Wrongful Birth" Claims and the Paradox of Parenting a Child with a Disability, 87 *Fordham L. Rev.* 583 (2018). Available at: <https://ir.lawnet.fordham.edu/flr/vol87/iss2/4>
81. Yee, E.G.X, Folashade, A.T. & Perveen, A. (2025). The Challenges Faced by Parents and Their Expectations towards Their Special Needs Children. *International Journal of Research and Innovation in Social Science (IJRISS)*, 2454-6186, Vol IX Issue XVII, Special Issue on Psychology. DOI: <https://dx.doi.org/10.47772/IJRISS.2025.917PSY0020>
82. Zhang, X.N., Zhang, S., Liu, C.Y., Ni, Z.H., & Lv, H.T. (2025) Caregivers' experience of having a child with Down syndrome: a meta-synthesis. *BMC Nurs*. 2025 Jan 20;24(1):66. doi: 10.1186/s12912-024-02652-y.