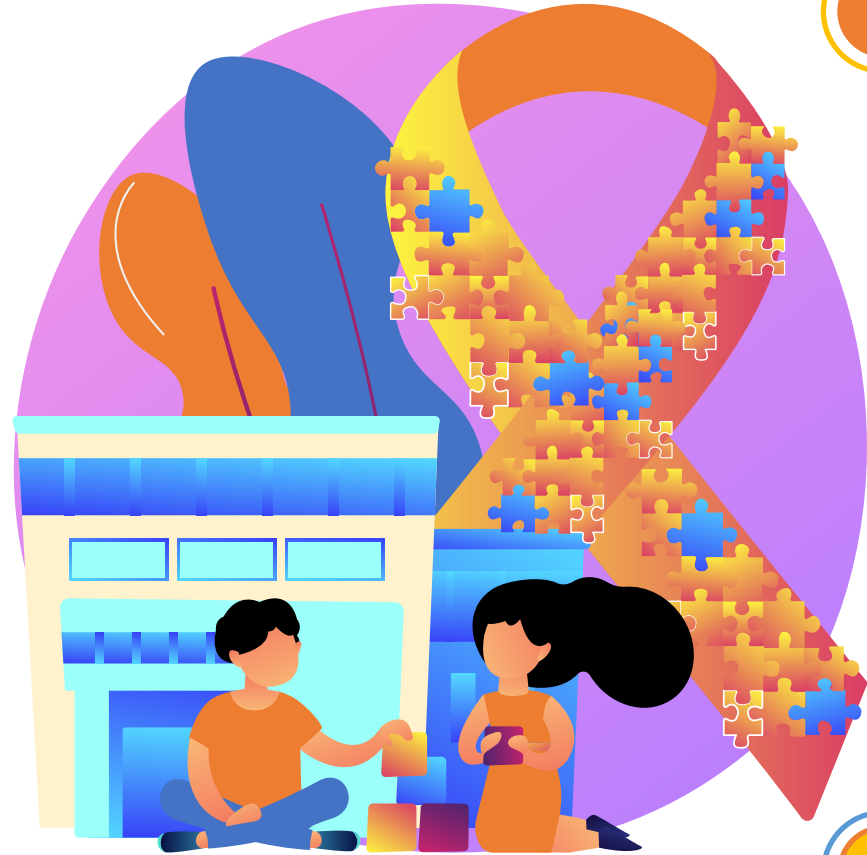


Factors Contributing to Stress among Mothers of Children with Autism Spectrum Disorders in Maldives

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Outline



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Background

-  Autism is a lifelong complex neurodevelopmental disorder, characterized by marked deficits in reciprocal social communication and interaction, as well as restricted repetitive behaviour and interest.
-  Some individuals may only be mildly affected whereas some may show behavioral deficits and excesses that drastically affect their ability to function (Anderson *et al.*, 2017). Many people with ASD are expected to have life-long needs with tremendous costs for individuals, their families, and society (Horlin *et al.*, 2014).
-  Robust findings demonstrate that parents of children with ASD experience high levels of parenting stress that exceed those of parents of children with typical development as well as other developmental disorders (DesChamp *et al.*, 2020).
-  Higher levels of parenting stress is associated with higher rates of parent psychopathology such as anxiety and depression as well as other mental health issues (Charmam *et al.*, 2016), negative outcomes for families such as low family quality of life, increased strain of family relationships, including higher rates of divorce (DesChamp *et al.*, 2020).
-  Prolonged exposure to stress may result in unfavorable medical consequences such as a reduction in mothers' immunity, hypertension and heart diseases (Gallagher *et al.*, 2009).
-  In addition, parenting stress may negatively impact the care-taking routine of the child and the overall effectiveness of interventions for children with ASD (Anderson *et al.*, 2017).
-  Therefore, it is important to identify these stress-inducing factors among mothers and equip them with strategies to better manage stress, to maximize the developmental outcomes of the child with ASD as well as the overall health of the family unit. Most autism interventions are focused on child-related interventions. It is important to focus on family-based interventions as well, to achieve better outcomes.



Significance of the study



The prevalence of ASD has been increasing worldwide, including in the Maldives. As per recent MOE reports, 4248 students with 'complex learning profiles' are enrolled in Maldivian schools, out of which 917 students have ASD, that is **21.58 %** (Department of Inclusive Education, 2020). Over 200 students were registered and seeking therapy in the year 2020 alone. Over 5,000 children have approached the center for consultations and various therapies (Autism Association of Maldives).



Parenting a child with ASD is a stressful and challenging experience, particularly in countries where numerous support services are limited.



Studies focusing on disability management, service provision, and needs analyses are limited in Maldives. In particular, ASD-related studies are almost non-existent when this is one of the fastest-growing disability in the country (Shaughy, 2017).



Studies report mothers have significantly higher stress levels than fathers (Fikriyah *et al.*, 2018). Maldives is still known to have deep roots in a patriarchal society where mothers are solely responsible for taking care of the family along with many other responsibilities, resulting in mothers being more vulnerable to stress than fathers. Hence, it is essential to identify these risk factors that contribute to stress among mothers to help them better manage stress.



According to Benson (2010), increased use of nonadaptive coping styles was directly related to higher levels of stress and distress, which in turn decreases the parental efficacy which may ultimately have negative impacts on the parent-child relationship, child development, and effectiveness of interventions for children with ASD (Fikriyah *et al.*, 2018). Therefore, maternal stress management is vital for the well-being of both mother and child.



Review of Literature



Raising a child with ASD is a remarkable commitment often for a lifetime, where the caretaker is subjected to a great amount of severe stress. Several factors may contribute to stress. Some factors identified from existing literature:

Child-related factors

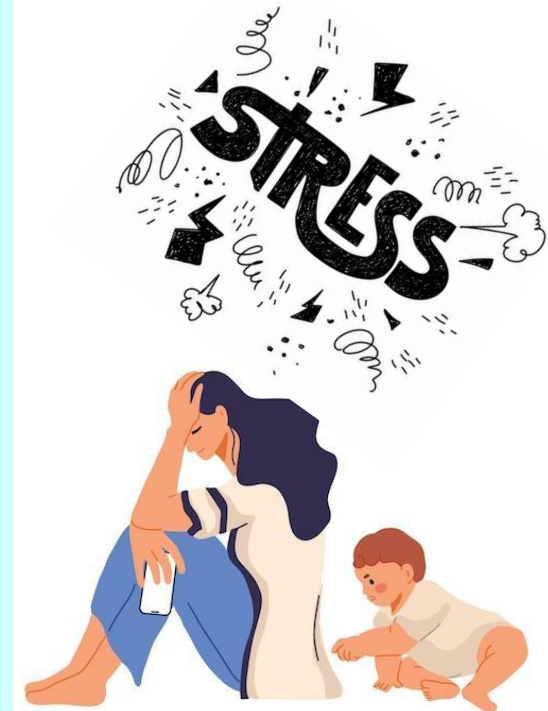
- ASD severity and child's level of adaptive functioning: stress among parents is largely produced as a result of the child's inabilities in emotional, social, and cognitive development (DesChamp *et al.*, 2019).
- Comorbid conditions & presence of multiple disabilities (Amireh, 2018)
- Challenging behaviours account for approximately 25% of parental stress (Rivard *et al.*, 2014)
- Period of transition into adulthood: many individuals with ASD face significant obstacles in multiple areas as they attempt to navigate their way into college, work, community participation and independent living (Henderick & Wehman, 2009).

Mother-related factors



- Low maternal education level, Parents' low Sense of Coherence (SOC), and low Parental Self Efficacy (PSE) also emerged in the literature to signify high stress among parents of children with autism (Batool & Khurshid, 2015).
- Maternal employment status: employed and work-outside-home moms had higher stress levels than work-from-home moms, unemployed moms had the highest level of stress (Fikriyah *et al.*, 2018)
- Higher level of adversity intelligence level is associated with lower level of stress (Fikriyah *et al.*, 2018)
- Spouse support (Papadopoulos, 2021)
- Coping mechanisms and strategies utilized (Troy *et al.*, 2007)
- Acceptance of diagnosis duration (Khan *et al.*, 2016)

Environment-related factors

- Provision of health services (Matenge, 2012)
- Provision of educational services (Sosnowy *et al.*, 2017)
- Unfriendly hospital environment: lack of effective communication and accommodation of sensory challenges in hospitals; rigid health care provider and hospital organization (Hall & Graff, 2011)
- Social stigma, judgement on parenting ability (Muskat *et al.*, 2014; Staniland & Byne, 2013; Conolly, 2016)
- Parent-professional relationship (Khan *et al.*, 2016)
- Social support and social capital (family & friends) (Khanlou *et al.*, 2014)
- Community awareness and culture (patriarchal culture increased stress) (Papadopoulos, 2021)
- Delays in getting a diagnosis, acceptance of diagnosis and coping with the changes in family dynamics (Gomes *et al.*, 2015).
- Limited access to vocational and higher education opportunities (Sosnowy *et al.*, 2017)



Objectives & Research Questions

-  **Objective:** To explore the factors contributing to stress among mothers of children with ASD
-  **Research question:** What are the factors that contribute to stress among Maldivian mothers of children with ASD?

Methodology

Data Analysis

- Content analysis method

06

Research Approach & Design

- Interpretivist paradigm
- Qualitative approach
- Phenomenology

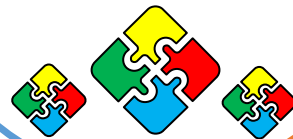
01

Reliability & Validity

- Expert review & pilot testing of interview guide
- Member-checking
- Reflexivity

05

Methodology



Sampling

- 8 ASD mothers (residing in Male')
- Purposive sampling (different levels of severity, age 5-15 yrs, different educational background, working/stay at home)

02

Ethical Consideration

- Informed consent
- Right to withdraw
- Voluntary participation
- Confidentiality & anonymity

04

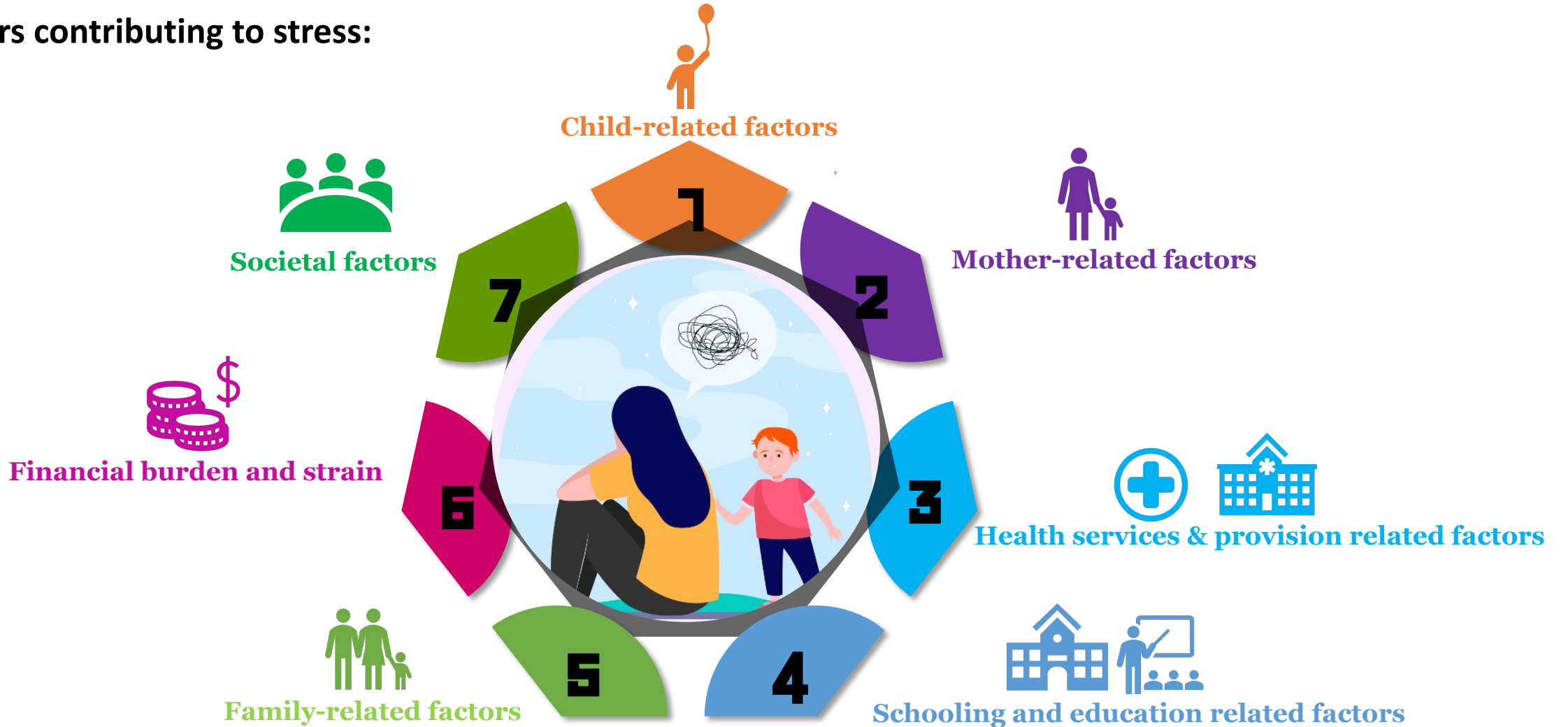
Data Collection Method & Procedure

- Open-ended, Face-to-face, Semi-structured interviews (45 minutes- 1 hr)
- Tool: Self-developed Interview Guide

03

Findings & Discussion

Factors contributing to stress:



Findings & Discussion

1

Child-Related Stressors

- Due to **difficulties in social and motor skills** in individuals with ASD they require constant assistance. Six out of eight mothers mentioned they are **physically expected to assist and meet the demands of their children** even in difficult circumstances often leading to ill health of mothers. Almost all parents admitted to having challenges directly caused by the enormous **care burden** for children with ASD which leads to increased stress.

“Even as I got pregnant with my daughter, I would carry him to school every day. Till my delivery, I continued. Only on days when I was really sick, I couldn’t take him to school, as I was not able to carry him” (P.2).

- Children who have severe needs due to **atypical behaviours, sensory issues, feeding issues, sleeping issues,** and **communication difficulties** were particularly stressful.

“It is not easy to feed him healthy food, there’s only a limited variety that he eats, so it is very difficult to feed him, especially when we are traveling. This limits our traveling options too” (P.1)

“She can’t talk yet. She is almost 7 now. Whenever she gets frustrated she bites herself (hand). Her whole hand is covered with scars. We keep her hand bandaged to prevent her from harming herself further. I feel helpless when she is harming herself” (P.3)

“Sometimes she would try to tell me something and I would not understand. The look in her eyes is heartbreaking. I wish we could communicate better” (P.6)

“She wouldn’t wear just any type of cloth. School uniform material is uncomfortable for her. We had to request the school to allow her to wear her usual clothes to school, but they wouldn’t allow it. So most days we had to keep her home. Some days are particularly hard” (P.7)

2

Mother-related Stressors

- **Lack of awareness about Autism**

“I realized I lacked a lot of awareness and it led to a lot of delays in him. I didn’t know how to deal with the situation back then” (P.4)

- **Lack of proper coping strategies:** Mental exhaustion was the main prominent concern participants shared experiencing it almost on a daily basis. Exposure to **long-term mental stress** has had bad consequences where some participants have been diagnosed and treated for **psychiatric disorders** such as depression and anxiety.

“I was diagnosed with depression and anxiety. Had to seek professional help” (P.5).

“No parental support was available. I had to do my own research. I joined online support groups of other countries which helped a lot” (P.6)

- **Not prioritizing own self and well-being:** Taking care of a special needs child requires a lot of time and commitment. This results in **no self-care time** for mothers adding more stress and making them more **disconnected** and **isolated**.

“Not enough time as I need because of the time consumed to take care of a special needs child” (P.5).

- According to participants **going out or spending time with others** along with the child with ASD **added more stress and anxiety** due to being overly cautious and protective. Due to the complex nature of ASD it is also **hard to leave the child in care of other people**.

“Family gatherings.....that was scary! Even if we were invited.....we don’t want to attend a gathering and he might do something. The tension of things like that!! And we don’t want to go without him either, also it is difficult to keep him with someone and go” (P.2).

- **Vicarious futurity**

“I am constantly worried about his future. Will he be able to marry? Will he be able to work ?” (P.2)

“I am scared and worried about how he can be out in the society and contribute when he becomes an adult. I think about the kinds of job options for him, and the working environment (due to his sensory issues)” (P.6)

Findings & Discussion

4

Health services related stressors

- All participants except for one mentioned the **difficulty in acquiring the required services** regularly, noting that ASD is a lifetime disability that would require continuous technical and specialist interventions. Some participants have mentioned that getting **timely appointments** is a difficult task. Sometimes **waiting time** can prolong for months without getting proper services.

"They put me on a waiting list, and I got an answer after 3 months. After 6 months into diagnosis, I quit my job and stayed home just for him" (P.7).

- Lack of quality and specialized therapies** is a prominent issue. Some had to **migrate** overseas in search of quality therapists due to the lack of progress of their children.

"From Male, we did receive therapy but didn't see much improvement, so we went to India...there we saw a lot of improvement" (P.4).

"The therapists are not qualified. Some clinics make even the receptionist give therapy" (P.7)

- Uncertain** about their children's future due to the lack of specialized therapies available.

"Very hard to get appointments for sessions. Especially vocational or skill-based therapies. Even though he is exceptionally good in academics, he lacks adaptive skills which is the most important thing for him now. I am scared and worried about how he can be out in the society and contribute when he becomes an adult" (P.6).

- Due to limited accessibility to therapy and health services from public hospitals, many **private centers** have started therapy, but at a **higher cost**. Many of the participants have raised concerns related to the **affordability of the services**.

"It's expensive compared to other countries, therefore it's difficult to take regular therapy sessions. A lot of money goes from our own pocket" (P.5).

- Mothers showed concerns over the **lack of professionalism, skills, and attitude** of some therapists

"Some therapists would talk negatively about his behaviour in front of him. They need to have more empathy, and understand that even though my child is non-verbal, it doesn't mean that he can't understand what she is saying."

5

Education-related stressors

- Lack of **equal opportunities** despite the call for inclusive education.

"At first it was very difficult. Schools rejected and didn't accept my son and some schools didn't give the opportunity" (P.5)

- Often these vulnerable children are subjected to **bullying** and sometimes **pressured** to perform as the 'neurotypical' students by some teachers, subjecting them to more mental pressure resulting in non-favorable outcomes such as **behavioral issues**. This can be a result of **lack of awareness** and **limited training** for teachers to build the **capacity and skills** that are required to cater to a child with special needs.

"Some teachers had the mentality of not thinking of him as a child who will need special attention. So, their expectations were very high and to meet up to their expected level was difficult" (P.1).

- Lack of **peer group awareness and other parents' awareness**

"He used to get nasty comments from parents as well as school kids. Some have said out loud things like "bad boy" at him while he was having meltdowns"(P.8).

- Lack of appropriate **resources** including **human resources** and **infrastructure** caused tremendous stress among parents and have caused despair during times of need. Proper "calming rooms" which in many cases help deal with violent outbursts and other involuntary behaviors are still unavailable.

"It was very, very difficult. He would bite kids, fight and kick kids, and would damage things. It was sadder to see him damage other kid's stuff than his own" (P.7).

"He used to tear books at school, stomping his feet and walking vigorously, shouting out loud and walking out of the classroom, coming home and banging the door" (P.6).

"We had to pay 2,000/- for a separate Shadow Teacher... If the Shadow Teacher is absent, he is not allowed to come to school"(P.4).

"One time I sent my child's nanny to school to an event with her, to calm her down if she has a meltdown. After that day, every time a special day is celebrated, the school requests us to send her nanny with her to school because teachers cannot look after her during events" (P.5)

Findings & Discussion

3

Family-related Stressors

- When a child is diagnosed with ASD it's not just the child who is affected, there is a **change of the whole family dynamics**. Mothers described the difficulty they experienced in communicating with family and sometimes with spouses. This is also because of the **insecurities and misconceptions** which come along with ASD.

"So first I had to overcome his insecurities. He (husband) couldn't handle the misconceptions regarding this...he's very supportive and very helpful and caring to our child. But the saddest part was that, apart from his parents, he couldn't even share it with his friends or extended family" (P.7)

- Taking care of a child with ASD throughout the day resulted in **limited quality time** available with other family members, affecting the **relationship with the spouse and other children**.

"It was only after we put the kids to bed, we would get some alone time to think deeply about our life now. Sometimes, I would be too tired and fall right to sleep...both of us cannot go out together"(P.7)

"Tasks I could do in a short amount of time with my normal kid takes much more effort and time with my autistic child. It takes more energy, it's more like a challenge" (P.3)

- Maintaining a healthy social well-being for the mothers is also difficult due to **lack of support** from extended family or community groups.

"Actually, I need some time outside the home. Even if it's for an exercise class. Then I need someone who can take care of him" (P.4)

6

Financial burden

- Even though the national social scheme alleviated some of the financial burden to an extent all participants spoke about financial strain as **household income was solely dependent on just a single parent** mostly.

"The fact that only one parent can work to earn money and the other must always stay with the kid at home...even staying home cannot give equal time to all the kids so everything is a challenge" (P.3)

- Due to **limited access** to diagnosis and therapy services from government institutions parents seek services from **private centers** which are **expensive**. This also **reduce the quality of life** of the family.

"Difficult to continue therapy as it costs over 500 per session. Weekly 2 sessions, sometimes I have to just be okay with 1 session"(P.4)

- Due to **lack of services in the islands**, many are **forced to migrate** to the capital seeking basic services.

"We are renting here in Male'. Moving back to the island is not an option. A lot of money goes for rent too...money I could have spent on my child" (P.4)

7

Societal stressors

- All participants expressed unhappiness about the society they live in due **to lack of empathy** from the general public and some community members. Mothers also expressed the level of **stigma**, **discrimination**, and **judgment**, especially from other parents which contributed to increased stress.

“The lack of understanding from people around you, not accepting that their “behavior” is due to a disability”(P.3)

“Once he went and sat near some kids eating at a table with their parents...that parent got annoyed and very rudely told me that I should take him away from their children”(P.8)

- **Lack of awareness** among relatives and the general public has also **escalated mental stress** for mothers and often put mothers in positions where they had **to justify the child’s behavior** and other issues to people around.

“They commented saying, ‘Why aren’t you talking? Doesn’t your mom talk to you?’ ... things like this were said... it was difficult for me to tell them why he was behaving that way” (P.2).

“People will say he is like that because I give him too much screentime and because of the way I parent. Blameful comments like that are made” (P.2)







“Most people do not know the difference between Autism, ADHD and other non-visible disabilities. All of these kids are autistic for them, and they generalize” (P.3)

“We are advised to take our kids to playgrounds and parks, but as other kids are not taught or are not aware of the behaviours of autistic children, it’s difficult. Because they are also not taught the proper way to play with different types of kids” (P.1)

- **Lack of disability-friendly playgrounds**

“Parks and play-spaces in Male’ are crowded. Often these spaces are very open. I’m always anxious if we take him to a park, we fear that he might run outside... it’s not safe” (P.2)

Conclusion & Recommendation

-  The findings of the research have important implications on devising better policies and interventions to improve the health and education sector in the country.
-  It is recommended that the government must establish **more affordable and quality** therapy and treatment centers.
-  Establish **better monitoring and regulation** of private health service providers.
-  Conduct **more awareness** programs within schools and health centers focused on dealing with individuals with disabilities.
-  Promote **community-based rehabilitation** and **support groups**.
-  **Train more professionals** in the areas of specialized education, speech therapy, occupational therapy and behaviour therapy.

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