

FAQs: Living with Autism

- This paper sought to explore three questions:
 - **What is the nature of the challenges faced by parents of children with autism?**
 - **To what extent do income levels mitigate these challenges?**
 - **What are the most pressing problems faced?**
- Four key areas were examined: education and care, healthcare, family and society as well as long term planning.
- Three in-depth interviews were conducted with families from low, middle and high income brackets.
 - High income (monthly per capita earnings more than RM3000)
 - Middle income (monthly per capita earnings of RM501 to RM2999)
 - Low income (monthly per capita earnings less than RM500)

1. What are the education-related challenges faced by parents of children with autism?

- **Access to suitable educational pathways.**
- **A shortage of educational institutions that are able to handle and accept children with autism**, resulting in a shortage of qualified special needs educators. Many affluent parents respond by establishing privately owned special needs schools or centres.
- There are objectives to “inclusive education” programmes, which believe that “all children should learn together, wherever possible, regardless of the differences of difficulties they may have.” Currently, only 6 percent of students with special needs in Malaysia are enrolled in inclusive programmes. **Other parents fear that special needs children will “slow down” or “disrupt” their own children’s learning.**
- **There is a shortage of qualified caregivers**, so the weight of caring for children with autism often falls entirely on their mothers. Respite or replacement care, which provides trained caregivers for short periods of time to allow parents their own time, is rare.

2. What are the healthcare-related challenges faced by parents of children with autism?

- **There is a shortage of specialist care.** Waiting lists are typically long, going beyond a year for some highly sought after specialists.
- **Misdiagnosis by general practitioners** is a common complaint. Conditions distinct from autism may present symptoms similar to those of autism.
- **Regular health visits unrelated to autism may be challenging**, because there is little understanding or accommodation of these children’s needs.

3. What are the family- and community-related challenges faced by parents of children with autism?

- Parents without a typically developing child may feel compelled to try for another child that would be “normal,” when in fact the **risk of autism recurrence in siblings is 2-18 percent**.
- **There are superstitious practices used in hopes of “curing” autism**, resulting in conflicts between these beliefs and more modern, medically accepted therapies.
- **Social discrimination** towards children with autism.
- **There is a lack of autism-friendly spaces**, even though many of the changes needed involve relatively low costs.

4. What are the long-term challenges faced by the parents of children with autism?

- Most of the support for individuals with special needs is focussed on children, **reducing dramatically as they transition into adulthood**.
- Employers often **misconceive** that all individuals with autism are merely suited towards **low skilled, repetitive tasks**, when many of them have average or above average intellectual ability, and can be extremely gifted in certain fields.

5. What are the most pressing problems faced?

- **The lack of services for adults with autism** is a critical gap in the current provision of services.
- **Arrangements to support independent living** are currently non-existent.
- **Employment opportunities** are limited.

6. How can these issues be addressed in Malaysia?

- **Ensure training and awareness for a wider audience** -- from increasing the number of well-trained teachers, to targeting all medical practitioners and not just those specialising in autism.
- **Provide more comprehensive forms of care**, including respite care, through public and private parties.
- **Offer targeted and flexible financial assistance** to parents of children with autism. Rather than limit low income parents to public services, **vouchers for private services** could be provided.