



# ADDRESSING SOCIAL AWARENESS AND SUPPORT TOWARDS WELL-BEING AND PSYCHOLOGICAL STRESS IN PARENTS OF CHILDREN WITH AUTISM SPECTRUM DISORDER (ASD)

*A Policy Note of  
SOCIETY, BEHAVIOUR  
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## INTRODUCTION

### What Is Autism Spectrum Disorder?

Autism Spectrum Disorder (ASD) can be defined as a complex developmental disability that commonly incorporated persistent challenges in social interaction, speech and non-verbal communication which commonly associated with restricted or repetitive behaviours. ASD normally appears during the first three years of life due to a neurological disorder that affects the functioning of the brain. The prevalence of autism is reported to be four times more in boys in compared to girls. Autism owns no racial, ethnic or social boundaries, and cuts across family income, lifestyle and educational levels.

**“Autism Spectrum Disorder (ASD) affects an estimated**

**1 in 54**

**for every new-born”**

*(Centers for Disease Control and Prevention)*

## CURRENT SITUATION

There are few unresolved issues in regards to the impact of ASD, which is not only towards the children but also the people around them, such as society, family, school teachers and friends. Parents of children with ASD tend to experience a higher level of mental fatigue and reduced overall wellbeing, for instance, carrying greater stress, anxiety and depression, compared to parents of typically-developing children (TD) or children with other disabilities.

The main contributor of stress among parents with ASD children is the severity of the autism symptoms (Ilias et al., 2018). ASD has three level of severity, with each indicating a different degree of need for support. Hence, the response of parents and families to children diagnosed with ASD would vary from family to family (Ilias et al., 2019). Mothers tend to quit their job in order to become housewives, considering full care and focus could be provided to their ASD children since parents often experience stress upon learning their ASD children behaviour and diagnosis.

Unlike western countries, parents of children with ASD in South East Asia recorded higher number of prevalence in dealing with social stigma (Ilias et al, 2018). Parents in Malaysia received lower social support due to cultural differences and Malaysian’s public perception which subsequently serves as one of the major contributor of stress (Ilias et al., 2019).

According to Ilias et., al (2018), Asian community majorly believed that ASD is something bizarre which interconnected with mystic means. Certain society owns a perception that having an ASD children is somehow related to the past mistakes committed by the parents that caused the disorder. Although majority of mothers did not believe the statement, however, at certain degree, they felt stigmatized by this societal perspective which consequently affected their wellbeing (Resurreccion, 2013).

Previous studies highlighted the stress-linked factors among parents with ASD children is mainly due to lack of support from the surrounding. The society play a vital role in influencing how parents of children with ASD interact within the community. Financial status however brings the additional merit to stress among parents with ASD children.

Parents with ASD children who come from high-socioeconomic status were reported to feel competent, supported and well-adjusted in their role as parents. However, parents with low and middle income status always feel like they are not doing well in parenting skills and not providing adequate needs that their ASD children require.

Studies done by Konstantareas & Homatidis (1989) summarized that, unlike the older parents, younger parents who are below 40 years old experienced greater stress due to many adjustment problems and low confidence in parenting ability. This situation brings negative impact not only towards the child growth but also increase challenges of getting social support (Ilias et al, 2019).

In regards to the adjustment problem, younger parents commonly experience difficulties in making decision to place their ASD children at either a special school or at mainstream school. However, older parents are able to make use of more resources in maintaining social support, build meaningful network in the society and more knowledgeable of available services they could make use of (DeLambo et al., 2011).

## RECOMMENDATION

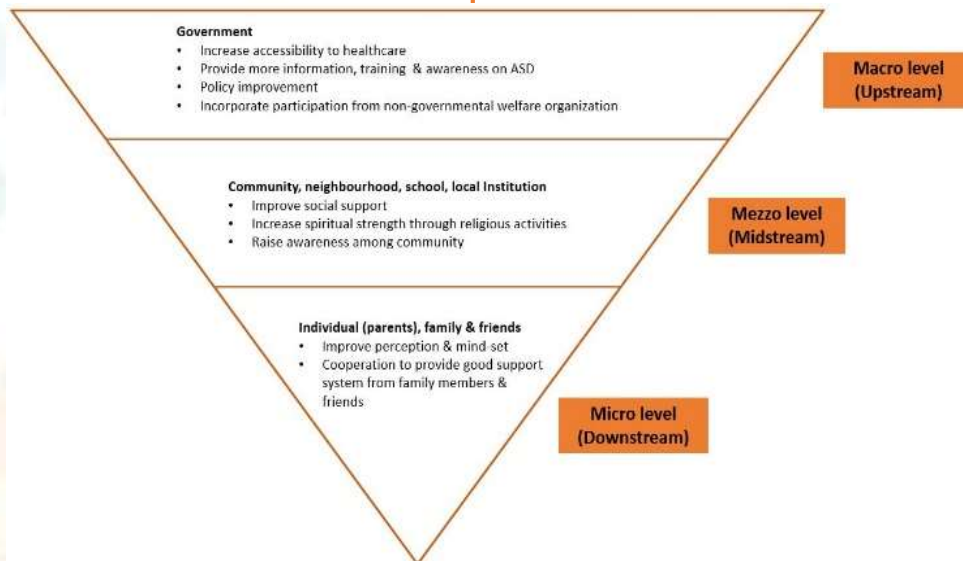
### Upstream Level: Roles of Government

Considering the behaviour of ASD children as the main contributor for parental distress, the government should enhance education amongst parents by providing better services and room of opportunities to increase their knowledge and understanding regarding ASD. Preventive measures could be taken for younger parents in order for them to have a better preparedness to cope with future challenges. This could be done by incorporating the assistance of more non-governmental welfare organization such as The National Autism Society of Malaysia



(NASOM) which serves as a platform to have a better access for therapy and health services for their children.

gather the social support (Ilias et. al., 2018; Ilias et. al, 2019).



Most parents with ASD children experienced massive challenges due to poor policy and financial support. In regards to this matter, the government should imply action in improving policy and financial aids for special needs and wellbeing. This is in line with previous research reported that SEA region face an imperative need for more resources and support services (Ilias et al., 2018). More comprehensive care and financial aids must be provided to children with ASD and their family especially those who live in suburban and rural areas.

### Midstream level: Roles of society and religious

**B**asri & Hasyim (2019) addressed that strong support from the community may contribute to the perception of safe environment and reduce their burden. In societal context, religious belief plays a significant role in facilitating parents with ASD children to deal with stress, especially among the South East Asia countries. The Asian parents managed to receive strength and positive support which were embedded within the religious belief that their child is a present from God. It was reported that, whenever parents are able to value the special condition of their children, they tend to find comfort and control their stress through prayers, reading holy books and involving in religious activities to

More collective outreach efforts should be carried out through schools, religious centres such as mosques and churches. Family members could assist in providing more information and exposure about available services for parents with ASD children. Information and talks should be promoted more aggressively through local and online media platform, considering strategies to tackle suburban and rural areas where internet accessibility is limited.

### Downstream level: Roles of parents and family members

**P**arents with ASD children tend to get stress initially when they could not be able to understand their children's wants and needs which commonly been expressed through aggressive behaviour and tantrum. However, stress can be reduced once they acknowledged that the way they perceived their children's condition would affect the learning progress (Ilias et. al, 2019). Hence, the key point would basically refer to the mind-set and perception of the parents to have a self-control in dealing with emotional and physical stress towards their ASD children. This could be done with full cooperation and good support from family members and friends around them which would increase the feeling of competence and support as parents.