



Support on Families with Autistic Children: An Exploratory Research

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Authors' contributions

This work was carried out in collaboration between all authors. All authors read and approved the final manuscript.

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ABSTRACT

Aim: The aim of this paper is to exploratory research support on Families with Autistic Children. Objective research is needed for identifying helpful resources and helping families with autistic children.

Methods: The approximated number of participants that answered the questionnaire are 406 people and consists of men and women. Process data collection is through the research which circulated to participants consisting of families with autistic children. After the research was ends and data already gathered, the researcher will access data achieved forcleaning data and then data will be analysed.

Results: The results revealed four support resources is a best social support that is spouses (husband/wife), another child, grandparents, and doctors as the percentage of support provided are very high compared to support from other sources. To achieve the objective, researchers have identified the "helpful" and " very helpful" support of the autism family as a result of the research findings. If seen, these four groups have a great influence on the lives of parents while managing their children with autism.

Conclusion: Parents or guardians have identified many positive and supportive aspects that really help them at all levels of support available. To meet the needs of these autism children, parents or

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guardians need to find the best source of support to produce quality attitudes that are caring, knowledgeable and caring in other communities. Parents or guardians specifically require the support of outsiders as the support is flexible and can find dynamic needs to meet the needs of families with these autism children.

Keywords: Autism; social support; questionnaire; autistic children; families; Malaysia.

1. INTRODUCTION

This study discusses the implications of parents or caregivers to their children with Autism Disorder and how their social support perceptions help in raising their children health and well-being. Objective research is needed for identifying helpful resources and helping families with autistic children. Social support consists of spouses, children, parents, stepmothers, relatives, friends, neighbours, employers, autism associations or clubs, non-governmental organisations (NGOs), teachers or school, and doctors. Social support is very important as it encourages parents to be less stressed in raising autism children for the coming days. This is because the pressure they face is quite high and it is likely that some parents out there have to spend time on their children treatment. They will undergo stress with the surroundings, financial stresses, and stress at work [1].

In addition, it is also a stress for many reasons and parents often report their level of stress over other parents as they raise autism children themselves [2]. In comparison, studies focus on the role of external support including social, professional support, duration of support provided, and the role of parents in determining their well-being [3]. Social support is very important as it reduces grief, stress, and can improve the normal family well-being. Children with autism can be a cause for parents to experience stress, emotion, and mental stress because the environment and life they face do not align with other people's lives. Autism that is experienced by children will damage their interaction and daily life as it appears at the beginning of the growth of children and it will be a source of stress to parents to deal with this environment [4].

This autism is also detected in children between the ages of 12 months to three years who are seen to be slow in their development, social skills, or language development [5]. Children with autism are usually live in their own world [6]. Children that suffer this autism can become a cause for their family to suffer from emotional

stress, emotion, and mental because environment and life that they face not in line with other person's life [7]. Autism experienced by children will harm interaction and their daily life because it appears in early children's growth and it will be a source of pressure to parents facing this environment.

2. LITERATURE REVIEW

2.1 Definition Autism Spectrum Disorder (ASD)

Autism Spectrum Disorder (ASD) is a brain development disorder that will have a great impact on the person suffering from this syndrome [8]. ASD are lifelong conditions severely impairing social skills and autonomy. According to the fifth edition of the diagnostic and statistical manual of mental disorders (DSM-5), ASD core features are: persisting deficits of social communication and interaction; restricted and repetitive behaviours, interests, activities [9]. In the diagnostic criteria, language abilities not employed in social communication have been de-emphasised. The DSM-5 redefined autism. Its predecessor, the DSM-IV-Text Revision, included five that is Autistic Disorder, Asperger's Disorder, Childhood Disintegrative Disorder (CDD), Pervasive Developmental Disorder, Not Otherwise (PDD-NOS), and Rett's Disorder, have been abolished [10]. In this DSM-5, Autistic Disorder, Asperger's Disorder and PDD-NOS are replaced by diagnosis of Autism Spectrum Disorder.

Additionally, the DSM-5 also reduces social communication impairment and repetitive behaviours, though the labels of Asperger's and PDD-NOS are still common use [11]. Children with this autism will have limited imagination to cause their behaviour in action to be repetitive [12]. This autism is common in boys, which is four times higher than girls. These autisms are also detected in children between the ages of 12 months to three years who are seen to be slow in terms of their development, social skills, or language development. Those with autism are usually in their own world [13]. Among the

features of autism are slow motor development, wanting excessive attention, less movement, repetitive action, no baby talk, no respond when called, no eye contact, less smile, and inflexible child. Parents are the closest group to these children and it is important for them to improve the development of these autistic children with various methods and therapies that can change their behaviour to better [14].

2.2 Concept Support Levels of Autism Spectrum Disorder

Every person with autism receives the same diagnosis such as ASD. But autism is a spectrum disorder, meaning that a person can be mildly, moderately, or severely autistic [15]. Many people also have additional associated symptoms such as intellectual or language impairments. DSM-5 diagnostic criteria include three "functional levels" each of which is defined based on the amount of "support" an individual requires to function in the general community [16]. Below are three levels, as described in the DSM-5:

i. ASD Level 1: Requiring Support

Without supports in place, deficits in social communication cause noticeable impairments. Difficulty initiating social interactions and clear examples of a typical or unsuccessful responses to social overtures of others [17]. May appear to have decreased interest in social in interactions. For example, a person who is able to speak in full sentences and engages in communication but whose to and fro conversation with other fails, and whose attempts to make friends are odd and typically unsuccessful. Inflexibility of behaviour causes significant interference with functioning in one or more contexts [18]. Difficulty switching between activities. Problems of organisation and planning hamper independence.

ii. ASD Level 2: Requiring Substantial Support

Marked deficits in verbal and nonverbal social communication skills such as social impairments apparent even with supports in place with limited initiation of social interactions and reduced or abnormal responses to social overtures from others [19]. For example, a person who speaks in simple sentences, whose interaction is limited to narrow special interests, and who has markedly odd nonverbal communication.

Inflexibility of behaviour, difficulty coping with change, or other restricted or repetitive behaviours appear frequently enough to be obvious to the casual observer and interfere with functioning in a variety of contexts [20]. Distress or difficulty changing focus or action.

iii. ASD Level 3: Requiring Very Substantial Support

Severe deficits in verbal and nonverbal social communication skills cause severe impairments in functioning, very limited initiation of social overtures from others [21]. For example, a person with few words of intelligible speech who rarely initiates interaction and, when he or she does, makes unusual approaches to meet needs only and responds to only very direct social approach. Inflexibility of behaviour, extreme difficulty coping with change, or other restricted or repetitive behaviours markedly interfere with functioning in all spheres [22]. Great distress changing focus on action.

2.3 Spouse Support

Support from a spouse is the most important support as it is the most powerful source of helping their spouses to equip their role in providing care, love, and education to their children [23]. Spouse support is the most valuable and crucial source of their spouse as it reduces the pressure they face. However, in the event of a divorce between spouses, the pressure experienced by the spouse is higher because no more strong supportive source plus the unhealthy condition of the parent will affect both individuals. In a study conducted in England, parents with autistic children consider their partner as the best partner and a very useful support [24]. The highest support is received from their spouse when parents have autism children aged less than one year to 18 years and above [25]. In addition, the spouse will be associated with their health and well-being better or less during the care of their children with autism and it is an important consideration in supporting each other. Spouse support gives strengths in raising autistic children and strengthening their households [26].

One study concludes that there is no important link between the two real parents or their other guardians as it indicates that autism is not an important predictor who can determine something about their relationship with their parents whether it will affect their family

relationship or not [27]. However, the findings suggest that there was a study on dissection rates of 381 adolescents and adults along with autism children between 1998 and 2004 [28]. This rate is compared to the divorce rate of 385 families due to the level of education, age, and gender of their child. These families are participants in an adult study in the United States. Although not described in detail the presence of autism children can affect their household, but it is closely linked that the support of the spouse is very helpful to equally develop their well-being with their children with autism [29].

2.4 Support Another Child

Support received by parents from other children is the second largest source of support for parents after their spouse. Their other children are siblings to their children with autism. Hence, sibling instincts help parents in reducing stress to take autism children. Other children should understand the nature of their parents and their siblings who have autism and encourage parents to manage their children with autism syndrome [30]. Therefore, support from other children is needed by parents to strengthen social skills in families with autistic children. The support received from their other children in terms of managing autism should necessarily result in a feeling of relief as these forms of assistance can reduce the burden they suffer [31]. The sharing of problems between parents and other children can overcome the challenges and implications that hold new parents with autistic children and improve their child development more effectively.

Furthermore, other children really understand and appreciate everything their parents have gone through in their twists and turn to care for their siblings with autism [32]. Support from other children is a platform for parents to learn the strategies of action in addressing the level of stress faced during the care of these autism children as well as to enhance the development of autism children from time to time through the support of their spouses and their other children [33]. Sources of support from other children are the most useful sources of support for parents who have autistic children because they think they understand each other's souls.

2.5 Grandparents Support

Grandparents and grandchildren are the closest sources of support to parents with autistic

children. They provide emotional and practical help to the parents to maintain harmony in caring for autistic children [34]. These grandparents are a blessing to parents as the aid to provide relief to parents and autism children themselves [35]. Additionally, these grandparents are also connectors to their children and grandchildren in the family. Grandchildren and grandparents are open-minded with the reception of their grandchildren who have autism because their instincts as grandparents are very powerful to show their affection for their grandchildren. Grandchildren and grandparents are the second strongest after parents and they will receive the frailty that happens to their own grandchildren. Their perspective is to approach parents and children of autism so that the family reaches a level of well-being like other families [36]. These grandparents accept the presence of their grandchildren categorised as special children. For them, the support given to the parents of autistic children will increase the confidence of the parents to care for their grandchildren who have better autism [37].

The statement is supported that these grandparents appear to understand the problems experienced by their grandchildren who have autism [38]. The presence of grandparents helps parents who have these autism children because of their positive influence on the parents will achieve their well-being in their family life. Parents have received the openness of other family members who want to help them [39]. Understanding clearly shows the best score to reduce stress, anxiety, improve their health and their well-being [40]. Parents also have a greater confidence in themselves to grow autism children. Parents need a lot of patience and endurance to care for autistic children and when there is a support they want to give it a relief for them, especially if the help they receive is from their own family.

Families are among the people most understanding of the problem. In this study family members are very familiar with the situation. They will provide strong support so that these parents are not faced with problems that can affect their health problems [41]. Parents need to be confident in themselves to enhance their ability to educate or care for autism children [42]. Furthermore, support from family members such as grandparents proved to be very helpful to parents as grandparents deeply understand instincts as grandparents and meet the needs of these autistic children. Hence, the support given

by these grandparents helps parents avoid experiencing high stress.

2.6 Doctor's Support

The doctor or therapist is an individual who helps parents in giving treatment or therapy to change the character of autism children in a better direction. Children with autism can be diagnosed through psychologists, psychiatrists, pediatricians or children's neurologists [43]. All these experts are eligible to provide autism children diagnosis if they have undergone proper training [44]. For these autism syndromes, the usual drugs to be taken by children are Serotonin Reuptake Inhibitors (SSRIs) such as Sertraline (Zoloft), and Orfluoxetine (Prozac). Some of these medicines have been studied and approved for use by children although not specifically for autism [45].

Doctors or therapists are experts who are able to transform children into better conversations, movements, visions and so on related to autism. At present, there is still no scientifically scientific medicine to treat autism [46]. However, there are still some medications that help other syndromes such as depression, seizures, and concentration problems. Studies have shown that this drug is most effective when combined with behavioural therapy [47]. Doctors are able to treat autism children by influencing the ability of autistic children to communicate and develop social skills [48]. Therefore, parents who have a child with different behaviour than other children are expected to immediately treat their children early so that aggressive behaviour can be reduced and able to turn out to be just like any other normal child. Parents who are beginning to see symptoms like autism should act early to go to meet existing experts as if treatment later, autism will affect the ability of children to communicate and develop social skills [49]. The support shown by the doctor is able to change the perception of parents that there is still a chance for their child to return to life like other children. This is because the parental pressure will increase if their child's health pattern does not change. Autism children may exhibit obsessive behaviour, including an intensive preoccupation with certain objects. This is because, some potential that can occur in children from mild to severe [50].

In addition, the doctor is also a psychologist to parents who have autism children [51]. Doctors will play their role in treating autistic children and altering the parents' mindset that their child has

the potential to heal [52]. Therefore, parents who experience stress as a result of having autism children need to change their perception that social support from the doctor is one of the best support because of the other position the doctor not only cares for their children but takes care of their minds by using a psychological approach [53]. Autism is often seen at the age of two and over with their development in contrast to other children [54]. Parents may be confused with their child's personality traits but if parents are professional, they will be able to detect their child with autism earlier [55]. Through the support given by the doctor or specialist, it is a dynamic support because doctors or specialists give parents exposure on how to care, medicine, support, skills, and so on to parents to practice at home [56]. Parents need such support as most of them are not exposed to such situations and therefore social support provided by doctors or specialists is able to alter parents' assessment of autism children and reduce their stress.

2.7 Family Counselling

Raising a child on the ASD can be one of the most rewarding and yet taxing things some parents will ever experience. In addition, to being therapist who works with families affected by ASD issues [57]. As autism parents, they should researching, finding, and financing all the right therapies for their kids. In order to survive this parenting journey, seeking professional help may be necessary at some point [58]. Below are four ways counseling can help a parent of a child on the ASD:

i. Adjusting To The Diagnosis

The autism diagnosis itself is often traumatic for parents. It can be a grueling process that may take up to year or more, with multiple visits to several different professionals [59]. During the process, parents are typically faced with myriad feelings, including anxiety guilt, excessive worry, hope, and fear about the future. Many parents end up being told that their child does not qualify for an autism diagnosis and are left at a dead end, with more questions than answer. Diagnosis or not, the grief is very real. Often, an understanding of the grief is cyclical, helps parents adjust [60]. Everyone reacts has a great deal to do with what happened and whether they've dealt with it appropriately. A person may need therapeutic interventions such as cognitive restructuring or therapy to help them get past the shock or pain of the initial diagnosis[61].

ii. Parenting Skills

Parenting a child on the spectrum can be very different than parenting a neuro-typical child. There are sensory issues to consider, educational decisions to be made, medical interventions, safety concerns, and therapeutic decisions, to name just a few [62]. More often than not, these children also have accompanying health conditions and self-regulation difficulties. Parents can become incredibly overwhelmed and confused when faced with it all. A counselor who is well-versed in the needs of autism spectrum families is crucial [63]. Such a professional can help parents prioritise needs and reduce the anxiety associated with overwhelm [64]. Often tell couples that a diagnosis of autism doesn't ruin a relationship, but their response to it might.

iii. Staying Connected To Your Partner

It has been reported that parents of children with autism have a slightly higher divorce and marital discord rate than parents of typical children. That certainly comes as no surprise, as the stressors are generally greater [65]. Autism tends to shine a bright light on whatever issues were already there. A counselor who understands the constant stress autism places on a family can help a couple navigate the difficulties while staying connected [66]. This doesn't happen overnight. It's a process that takes time, patience, and perseverance. But the results are worth it.

iv. Stress Management

Stress is a significant factor in the development of disease. In order to stay healthy, we need to learn to manage stress effectively [67]. The daily stress of autism parent is tremendous and constant. A counselor can help by offering a caring, supportive ear, validating parenting efforts and encouraging self-care skills [68]. Counseling can help someone through a rough patch or be used on an ongoing basis throughout the parent's journey.

3. METHODOLOGY

The research done is a quantitative study in the form of descriptive and the purpose of this study to identify helpful resources and help families with autistic children. The study uses 12 items of a questionnaire to get the findings, where the question focuses on support on families with autistic children and supported by previous

studies. Statistical analysis was undertaken to analyse a survey for the research. In this study, descriptive statistics were formed to know the amount and source of support percentage accepted by participants and fulfill quantitative research retrieval. The idea is then expanded from literature review and related studies on social support received by families with autistic children, where there are 23 question items in the questionnaire, then elements of literature review were used to form questions in the questionnaire so that it is suitable with the exploratory research support on families with autistic children, by adding specific questions about the support resources and suitable demographics.

3.1 Data Collection

The questionnaire was begun the process of collecting data is taken by participants who answered the research were made up of autism associations found in social media. The data were collected for a month from July 23rd, 2018 until August 22nd, 2018, where all participants could answer within the given time and all research findings were reported in statistical format. The approximated number of participants that answered the questionnaire are 406 people and consists of men and women. Among them are from Autism Malaysia and Cakna Autism Kelantan. This study is a system of data processing systematic [69]. This method is very important because it can fulfill the research findings required by the researcher. Therefore, researchers are scientifically aware of the sources of support obtained by families with autistic children. This study has used the research as a means of collecting data. The analysis was conducted to test the acceptance of social support in families with autistic children. Process data collection is through the research which circulated to participants consisting of families with autistic children. After the research was ended and data already gathered, the researcher will access data achieved and transplanted to Excel Spreadsheet for the purpose of cleaning data and then data will be analysed.

3.2 Ethical Issues

No ethical issues and participants are ready to answer the questionnaires given to them. The consent of all the information provided will be kept confidential and agreed by the participants. It also explains to the participants that by

completing the questionnaire provided, participants are considered to have agreed that the results received will be analysed and will be used in this research.

4. RESULTS

In Table 1 below shows participants for women above men. If seen in Table 1, female participants who answered the research were 60.34% ($n=245$) while men were 39.66% ($n=161$). The probability of a mother's instinct is stronger than men to rate them for the support they have received over the years. A total of 406 participants answered the questionnaire distributed over a month period. The results of the analysis which tested social support shows that participants aged 41 to 45 years old among the most participants answered this questionnaire. Percentage shows 23.89% ($n=97$). While participants aged 20 and under only show a small percentage of 2.22% ($n=9$). In Table 1, participants aged between 31 and 50 years old were the most participants who answered the research. The majority of participants who answered this questionnaire were biological parents (321/406). While in terms of race, the Malays among the most answered the questionnaire which is 83% ($n=337$). For the Chinese, Indians, and others who answered the research were 9.61% ($n=39$), 5.42% ($n=22$), and 1.92% ($n=8$) for the others. Meanwhile, descriptive statistics among study are presented in Fig. 1 about the resources social support perceived by families of the autism children. The findings of quantitative studies are summarised and discussed in relation to studies of support exploration on families with autistic children. The researcher will examine all findings and present the whole findings to analyse the data from the early stage to the end of the study and answer the objective of the study, identifying helpful resources and helping the families with autistic children.

Although the participants who answered the questionnaire were quite encouraging as most of them collaborated in responding to this questionnaire and helped the research to know the number of support received by families with autistic children. A detailed description of the research, as well as the intended of the results, were provided to parents. The research has been open for a month to participants answer the questionnaire and the questionnaire data was kept confidential so as to protect the anonymity of participants.

Table 1. Socio-demographic participants with autism children

Demographic variable	Families of autism children ($n=406$)
Gender	
Male	161 (39.66)
Female	245 (60.34)
Age	
> 20 Years Old	9 (2.22)
20-25 Years Old	28 (6.90)
26-30 Years Old	32 (7.88)
31-35 Years Old	77 (18.97)
36-40 Years Old	81 (19.95)
41-45 Years Old	97 (23.89)
46-50 Years Old	50 (12.32)
> 50 Years Old	32 (7.88)
Race	
Malay	337 (83.00)
Chinese	39 (9.61)
Indian	22 (5.42)
Others	8 (1.97)
Marital status	
Single	36 (8.87)
Married	351 (86.45)
Single Mother	12 (2.96)
Single Father	7 (1.72)
Relationship with autism children	
Biological Parents	321 (79.06%)
Foster Parents/Caregiver	13 (3.20%)
Grandparents	13 (3.20%)
Brother/Sister	29 (7.14 %)
Uncle/Aunt	30 (7.39%)

4.1 Helpful Resources and Helping the Families with Autism Children

For the social support source received by parents, as shown in Fig. 1, the combination of "helpful" and "very helpful" has obtained its decision that for spouses (husband/ wife) a percentage of 86.70% ($n=352$) another child 82.41% ($n=335$), grandparents 87.93% ($n=357$) and doctors were 96.06% ($n=390$). With this, positive sources of social support received by parents are from spouses (husband/wife), another child, grandparents, and doctors as the percentage of support provided are very high compared to support from other sources. To achieve the objective, researchers have identified the "helpful" and "very helpful" support of the autism family as a result of the research findings. In data that has been collected and analysed, the support resources that give this influence to parents are the support of the spouse (husband/wife), another child,

grandparents, and doctors. If seen, these four groups have a great influence on the lives of parents while managing their children with autism. Parents need the support of others because they can not afford to deal with this situation alone and take time to familiarise themselves with the situation of managing their children with autism. This given support will change their negative perceptions in a more positive direction.

5. DISCUSSION

The study was conducted to investigate the sources of support received by those who were living with autistic children and if viewed, it could be seen which sources are very helpful and very unhelpful. When viewed specifically, the immediate family members and doctors are the most helpful sources of support for families with these autism children. In this study, the spouses (husband/wife) showed a very positive percentage. Spouse (husband/wife) is the best social support. Their spouse is supposed to be at the same time facing stress while maintaining autism children. Various challenges and obstacles are encountered together. Therefore, spouses are a very useful and interdependent resource. In addition, parents also consider their partner a strong and mentally and emotionally supportive partner and source of support, and this study is also supported by other studies which also underscore that their spouses are the best partner and very useful support [70].

Furthermore, other sources of support from other children also provide good support in terms of

communication skills with their siblings who have autism. This is because the instinct of siblings is very strong and can help parents overcome the problems that their families face their lives along with autism children. Often other children will give their parents encouragement and encouragement to reduce the emotional stress and burden they bear. Support from other children is a platform for parents to learn strategies of action in addressing the level of pressure faced. This study is also supported when other studies have suggested that other children can reduce the problems experienced by parents to reduce emotional stress [71].

While support from grandparents is the strongest support for having a relationship with their parents and grandchildren. Grandparents will be an advisory expert for parents not to experience emotional disturbances, feelings of stress, confusion and so on. Their perspective is to approach parents and children of autism so that the family reaches a level of well-being like other families [72]. The last support received in this study is a doctor. Doctors are therapists. There is always much experience shared with parents about how to treat or care for autism children so parents can be prepared and calmly confronted if autism children experience certain problems. Doctors really understand parents and many things to share to enhance the ability of parents to care for autistic children and in terms of medicines that need to be given to children with autism. The study was also supported when studies have suggested that studies have shown that the most effective medication is when combined with behavioural therapy [73].

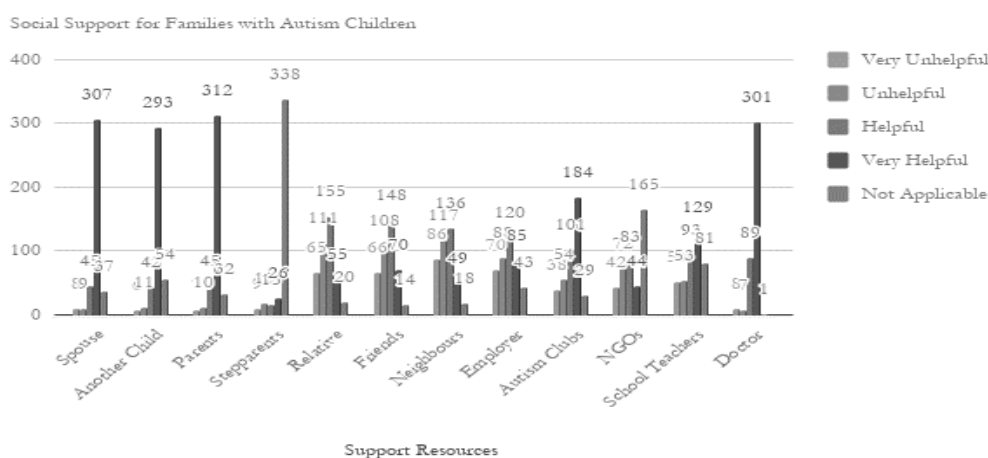


Fig. 1. Social support for families with autism children

6. STUDY LIMITATIONS

The study was aimed at obtaining social support received by families with autistic children. However, the research conducted only in Kelantan, Malaysia. Therefore, the results obtained were not representing all families with autistic children in Malaysia.

7. CONCLUSION

Overall, there are various support resources available to this parent. However, not all support resources will support them and most of them show very little support. Of the 406 participants who answered this questionnaire, it answered the objective of the study by identifying sources of support that helped families with autistic children. Parents or guardians have identified many positive and supportive aspects that really help them at all levels of support available. To meet the needs of these autism children, parents or guardians need to find the best source of support to produce quality attitudes that are caring, knowledgeable and caring in other communities. Additionally, families also need productive supportive resources to enable them to build their knowledge, understanding, and flexibility on specific needs for their children with autism. Finally, if autism children are accepted into society, it is a form of goodness to meet the needs of families with these autism children. Parents or guardians specifically require the support of outsiders as the support is flexible and can find dynamic needs to meet the needs of families with these autism children.

ETHICAL ISSUES AND CONSENT

No ethical issues and participants are ready to answer the questionnaires given to them. The consent of all the information provided will be kept confidential and agreed by the participants. It also explains to the participants that by completing the questionnaire provided, participants are considered to have agreed that the results received will be analysed and will be used in this research.

COMPETING INTERESTS

Authors have declared that no competing interests exist.

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