

Recognising Fathers with Autistic Children: Exploring Their Expectations of School

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Abstract

Although mothers are more commonly in control of their autism spectrum disorder (ASD) children, fathers are becoming more involved in the care of ASD child too. In this article, the authors present the fathers' expectations toward the school by describing the stories of three fathers of children with ASD who participated in this case study. In-depth face-to-face semi-structured interviews were conducted, highlighting their expectations of schools, given that they have children with learning disabilities. Thematic analysis has enabled the authors to identify, analyse and narrate on recurring themes that emerged from the qualitative interview data. Analyses of the interviews have indicated the emergence of seven main themes. Most of the fathers optimistically hope for: (1) enriched teacher training programmes, (2) practical teaching strategies, (3) ASD-friendly atmosphere and amenities, (4) trustworthy shadow aides, (5) enhanced parent-teacher communication, (6) reliable system and (7) reviewed policy. Thus, it could be deduced that the participants have a variety of expectations for schools in providing education and support for their ASD children.

Keywords: Autism Spectrum Disorder (ASD), autistic, fathers, expectations, school

Introduction

Fatherhood is steadily becoming more challenging nowadays. Fathers have to face today's anxieties like social media matters, peer pressure related to technology and fragile mental issues which fathers of the pre-millennium might not have to deal with. These challenges are harder to face up to when one of the children has learning difficulties. In a society like ours, fathers and mothers have separate roles and expectations. Mothers usually play the role of care and security provider. Fathers are expected to 'fix things', to oil the running of the home and the daily life of the family. Often when dealing with autism spectrum disorder (ASD) children, fathers will go through a gamut of emotions from the

feeling of helplessness to denial and frustration. Despite these reactions, perhaps fathers most accepted, essential role is to support mothers through this journey. Most times mothers need fathers to just listen, not necessarily asking fathers to solve problems. However, increasingly fathers are becoming more involved and more hands-on in the care of the ASD child. Although commonly mothers are in charge throughout the child's activities from speech therapy to swimming lessons, fathers are now voicing out that they feel excluded. Informative materials and resources on ASD children always set the target audience as the mother and not designed for fathers. This article could then in some measures address the lack of father-focused resources.

This article recounts a part of a larger study which looks at the experiences of parents with autistic children. It focuses on the expectations of fathers who are participants in the journey of parents and families with ASD children. Many studies and the subsequent resources have focused on the role of mothers as the primary caregivers to ASD children. The present study has attempted to fill in the gap and address the expectations that fathers of ASD children have of schools.

Past studies

It is very unlikely for parents with autistic children to have zero expectation, as parents by nature, always want the best for their children. With parents caring for autistic children, having certain expectations has become a role rather than a choice. Most parents, besides being the father or the mother whom the children trust and love, take up the roles as motivators when enforcing positive behaviours, as therapists when handling tantrums and behaviour excesses, and as researchers when looking for what's best for the children in terms of education. Ample studies show autistic children face detrimental adult outcomes leading them to be low-functioning individuals, which is mostly feared by parents who are caring for their growing autistic children. Adults with ASD often experience social isolation, few friendships (Orsmond et al., 2004; Whitehouse et al., 2009; Liptak et al., 2011; Howlin et al., 2013), and difficulties in pursuing and participating in post-secondary education (Eaves & Ho, 2008; Shattuck et al., 2012). Moreover, they are seldomly employed as they have limited independence in adulthood (Carter et al., 2012; Cimera & Cowan, 2009). And being dependent, they need constant support in daily activities (Farley et al., 2009; Taylor & Seltzer, 2011). All these boil down to how much an autistic child receives supports while growing up, and education is always the key.

Most parents have high expectations on the institutions that provide their children with necessary and effective learning that can prepare them for adulthood. Level of expectations is always correlated with the parents' educational level, employment, and social status (Hillary et al., 2017; Chianget al., 2012). Despite different backgrounds that affect the levels of intensity in the expectation, parents in majority perceive schools as the primary supportive entity that may help their children alleviate their struggles. Parents expectations of school ranges from the broadest issue, such as the curriculum, to the tiniest such as their child placement in the classroom. However, a significant number of studies has amplified parents' positive expectations towards inclusive education that is immersing their autistic children

within the mainstream system (Soltau, 2015; Wood, 2019; Elkins et al., 2003; Bashir Abu-Hamour & Mohammad Muhaidat, 2014). They believe that peer interactions will break the barrier between their children and others simultaneously, will prepare their children for adult life in an inclusive society.

Exploring Parents' Perspectives toward School

In many countries, studies have been conducted on parents' expectations towards school for their ASD children. Being parents, feeling worried and concerned about their ASD children is inevitable, hence many of them have shared their expectations towards schools that they send their children to. O'Hagan and Hebron (2017) proposed that schools need to be aware of the social experiences of pupils with ASD, and how they can be integrated throughout the school environment. Saggars (2015) emphasised that it is important to provide quiet areas with fewer people and give opportunities for pupils with ASD to work in smaller groups during the school day. Santos et al. (2016) reported that the social climate in the classroom is a key factor in the development of inclusive education.

Besides that, parents of ASD child also expect teachers to identify individual needs and appropriate supportive strategies, despite pedagogical experience and extensive knowledge of ASD. Researchers highlighted the importance of understanding pupils' strengths, identifying challenges, supportive strategies, and specific goals for achieving success. Humphrey and Symes (2010) reported that pupils with ASD face many obstacles that can prevent them from getting the most out of their education. In relation to this, previous research has suggested that pupils with ASD are more likely to be bullied and receive less consistent social support than children with other or no special educational needs.

Tobin et al. (2012) mentioned that parents with ASD child may have particular concerns about classroom placement, teacher qualifications, or the amount of time the child interacts with typical peers during the school day. For example, when parents believe that the school setting is a good match for their children's needs and have confidence in teachers' abilities, then they may be more optimistic and form more positive expectations for the school year ahead. Further, longitudinal studies among developing children have shown a positive, transactional relation between parents' expectations and children's academic performance, with parents' expectations and academic achievement predicting increases in one another over time (Briley et al., 2014).

Exploring Malaysian Parents' Perspectives toward School

In Malaysia, physicians, psychologists, and psychiatrists have been reporting an increase in the number of children with ASD referred to their clinics (Toran, 2011; Ministry of Health Malaysia, 2014; Neik et al., 2014). Furthermore, the number of children participating in special needs programmes is said to have doubled between 2006 and 2013 (Toran, 2011; Razali et al., 2013). These findings imply that additional autism-related research is needed in Malaysia.

Ilias et al. (2018) aimed to fill a gap in the literature by investigating the risk and protective events that lead to parental stress and resilience in parents of primary school-aged children with ASD in Malaysia. The inclusion of both mother and father participant viewpoints was the research strength. The themes centred around hardship and difficulty, as well as the parents' flexibility and acceptance. Other themes emphasised were parents' qualities and determination, as well as the protective events and procedures that assisted parents in developing and enhancing resilience.

Malaysian parents expressed that their children with special education needs (SEN)/ disabilities are welcomed in school by their able classmates (Nadzirah and Nik Nur Wahidah, 2019). In addition, the study also found that Malaysian parents emphasised that their child's capacity to interact with their classmates is a key indicator of social inclusion. Therefore, parents of children with ASD reported considerably higher levels of parental stress than parents of typically developing (TD) children. Another intriguing conclusion of this study was that parents of ASD children aged 30-35 were more worried than parents of TD children of the same age group. One probable cause is that their disabled child is in the process of transitioning into the education system, and they must decide whether to enrol their child in a special school or a mainstream school.

Low and Lee (2020) in their study described parents' experiences and goals for educational arrangements for ASD children in regular school. They found that during the school placement procedure, parents are not completely assisted. There are no specific restrictions governing children with ASD's educational settings. During school entry, parents are not usually given instructions on how to make educational choices for their children with ASD. Low and Lee (2020) also highlighted parts of the Malaysian school system in which initiatives at inclusion for students with ASD are not well-supported.

Methodology

The current study aims to delve into the fathers' outlooks concerning the schools or institutions for their ASD child. It is guided by the following research question: *What are the fathers' expectations of the school?*

This is a qualitative case study employing the purposive sampling technique. The main criterion of participant selection is being a working father of an autistic child. One-on-one, in-depth semi-structured interview sessions were conducted with three fathers ranging between one and a half to two hours per session. The sessions were recorded, transcribed verbatim and analysed thematically using the NVivo software. The researchers have carefully undergone the following procedures in the thematic analysis stage:

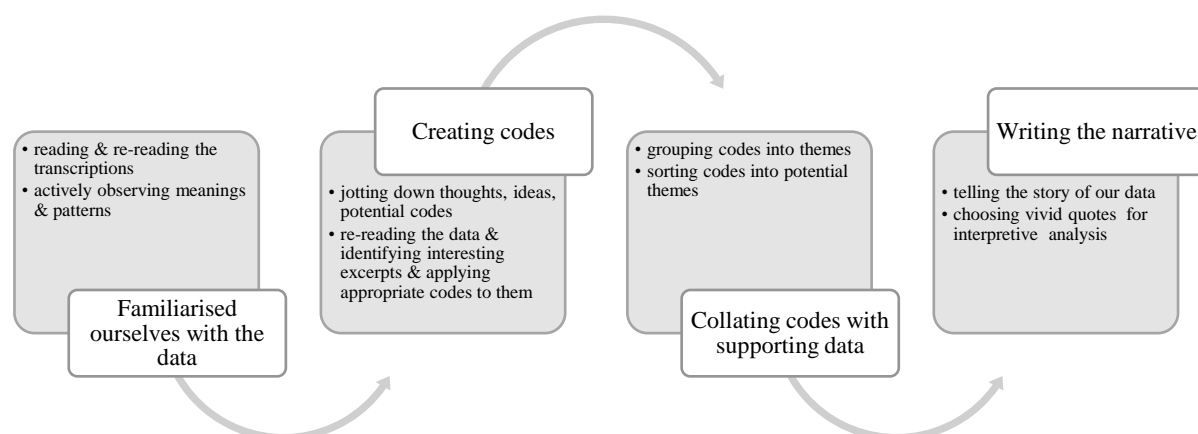


Figure 1: The walkthrough of the thematic analysis steps

The qualitative approach is used to allow fathers to share their stories and to enhance the ability of the researchers to understand the quality and enormity of the experiences they have. In line with the qualitative research design employed in this study too, a descriptive background of the participants involved is presented to provide the contextual setting. The three participants are Malay, Muslim professional fathers. Here, the identity of the participants is not disclosed but written using pseudonyms to ensure confidentiality.

Mr. Akram is a 42-year-old lecturer. His one and only child was found to have autism at the age of 3. He realised the abnormal development of his son at that age when his son was having speech delayed. His special son now is 14 years old and diagnosed to have nonverbal autism. He and his wife started to explore about autism via Google and found a local support group known as “*Persatuan Autism Muslim Malaysia*” and are among the pioneer members in Malaysia.

Mr. Khir who is 35 years old, detected his eldest son having autism at a very early age of one and a half years old. His son who has been diagnosed with a mild to moderate level of autism is referred to the paediatrician because there is no eye contact and speech delays. He sent his son to an autism laboratory attached to the Faculty of Education, Universiti Kebangsaan Malaysia, Bangi, for an intervention programme.

Mr. Amir is a 46-year-old master’s degree holder. At the age of 4, his youngest son was detected to have autism. His son is now 7 years old. He is fortunate to have strong support from members of his family. His father-in-law is even monetarily supportive of his special son's intervention. For his son, he chose a private school that specifically addresses the special needs of children with autism, which offers speech and occupational therapy.

Findings and Discussion

This section will provide the answers for the research question mentioned earlier, that is: *What are the fathers' expectations of the school?* Most of the fathers have various expectations of the school. By delimiting stories about their experience with their ASD children, several themes have surfaced which will be discussed in the following sub-sections.

Below is the NVIVO output of the major findings of this study. There are seven themes that have emerged from the data as illustrated in Figure 2.

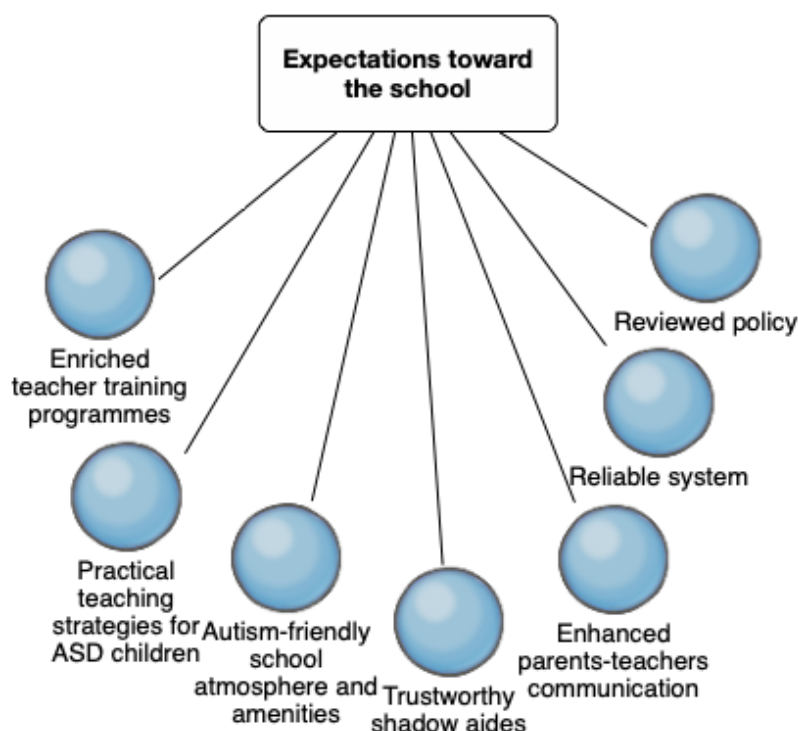


Figure 2: Fathers of autistic children's expectations toward the school

a. Enriched teacher training programmes

First and foremost, all the fathers interviewed feel that there is a dire need to provide quality training programmes for teachers so that the number of trained teachers can be increased. At present, although better than before, qualified teachers are still lacking.

"I think there should be more trainings for teachers because the current teachers still do not really understand (about autism). If I organise any workshops, not many teachers will join" (Mr. Akram).

"There should be more trained teachers who are well-equipped to entertain autistic children" (Mr. Amir).

The fathers also mentioned that the training programmes should be tailor-made more specifically about autism because for now, at schools the special education classes are a

combination of all types including learning disabilities and also physical disabilities, as iterated by Mr. Khir and Mr. Amir,

“If the school can provide trained teachers. The existing teachers teaching at PPKI (Program Pendidikan Khas Integrasi) [Integrated Special Education Programme] do not fully understand autism” (Mr. Khir)

“If they can provide very specific trainings for teachers so that all schools in Malaysia will have PPKI classes. And ... learning disabilities are varied – autistic, dyslexic, or speech delay. If there’s also speech therapist, it will be easy – everything can be obtained at the school. The normal speech therapists have limited experience with special autistic children” (Mr. Amir).

Another way to solve this issue is by promoting teachers to higher qualifications. A father suggested that one aspect is to upgrade the current available teachers to at least possess a diploma level of special education certification.

“I think the current teachers can also be trained. If not degree, diploma level is sufficient too” (Mr. Amir).

This finding supports previous studies (e.g.,Loi andMohd. Hanafi, 2017) whichhighlight that teacher trainingsarerequired to increase competencies in teaching and handling children with ASD. It is critical to emphasise that the Ministry of Education plays a significant role in providing special facilities and appropriate teacher training for special needs students in order to ensure more effective education for these children.

b. Practical teaching strategies for ASD children

The interviewed fathers also expect that teachers have knowledge of the initiatives needed to make a positive difference in their autistic students’ lives. Mr. Akram voiced out that,

“There is a special class, but they are mixed together – down syndrome, autism, slow learner etc. So sometimes, teachers will focus on the slow learners only. To me, personally, slow learner shouldn’t be in PPKI class, they should be in the ‘remedial class’. They do not have social problem like the ASD children. I think they need to revisit the policy. For example, if we want to treat a child about his or her learning, we have to properly treat that aspect. So, there shouldn’t be too many in a class. Because these children are very special” (Mr. Akram).

“As for me, we pay more than one thousand ringgit a month for a specific therapy at the school. I was hoping everything is inclusive there. So, I don’t have to fork out extra money. That’s my hope. I’m observing – for that amount, what are the benefits”. (Mr. Amir)

A father also expects that the school considers specific needs of the ASD children. Although he does not really know what comprises a special education syllabus, through his experience mingling with some support groups, he insists on suitable activities needed by his son.

“I am not sure myself about the special education syllabus. But based on my experience with the ASD communities, usually at school the number of staff is limited. So, maybe what teachers learn when they were at teacher training colleges or universities, they cannot implement fully. Maybe because of time too (Mr. Khir).

A father also said that teachers need to be alert and mindful of what the children need. For example, ASD children are comfortable with established routines.

“In the case of autistic children, we need to make them behave. Be quiet. If they arrive at school, enter the class. Sit down and listen to the teacher. Obey the instruction. That is what important. If possible, moving around, running. So, they will be trained ... And then when the teacher greets them. They will reply. And then if there's sing-along session, they can sing along. That's what they need. (Mr. Amir).

Many other studies (e.g., Sulek et al., 2021) recommend that future research should concentrate on increasing teacher knowledge and awareness of the existing research in the field, and beyond, that can aid their selection of classroom strategies to teach ASD children. Without teachers who are fully aware and well-equipped, students with autism may spend most of their time at school disengaged from learning activities (Muchetti, 2013).

c. Autism-friendly school atmosphere and amenities

Another theme that emerges from the analysis is to have facilities and features at school which are accessible for the autistic children. The fathers interviewed find it essential to have a conducive surrounding that can cater to their ASD child.

“... charts. At the toilet – what should be done first. There should be pictures numbered as 1, 2, 3 ...” (Mr. Akram).

“Yes, after turning the tap, sit. Turn on the tap again, the wash. So, the child will understand what to do – first, this, then that – before, after. So, they will know. And if a non-verbal child asks for something, like my son, he will show a card for example, he wants coco crunch – he shows a coco crunch card. And whatever he wants, he will show cards” (Mr. Khir)

“Activities ... like in the lab, there can be a trampoline for the children to let go their energy. The toilet, the dining area, the dish rack, sink – all should be at the level of the children's height (Mr. Khir).

“Perhaps, for government schools, the schools can be prepared 50% like kindergartens with therapy services which are privately owned, that would be good. Meaning, the school has

specific teachers, maybe 5-10 teachers, to train students like these. And maybe among those teachers, one is a qualified speech therapist. Imagine if each school has at least one. Only one, that's good enough. That's my hope. If the Ministry of Education can look into this. Maybe as part of these teachers' career advancement. If diploma or master programmes within this field, maybe many are interested" (Mr. Amir).

"If they can provide facilities together with trained teachers so that the school is a perfect place. For example, at the centre I'm sending my son, there are literacy, numeracy courses ..." (Mr. Khir).

Having this 'ideal' school, the dads interviewed do realise it incurs high cost. One of the fathers proposes that there should be more well-equipped centres that are catered for the low-income families. Mr. Khir is grateful that he could afford to send his son to a special school, but he is concerned with those who are less fortunate in terms of monetary.

"Alhamdulillah, I think I can afford to pay for my son's education. But others may not – what will happen to these children? They have many commitments which do not allow them to send their child to good centres. So, perhaps the government can add more centres. And also, awareness. Maybe government has done some actions, but the society might not be aware" (Mr. Khir).

Here it is evident that the fathers envisage a certain level of facilities for their ASD child. Other studies have also found that early diagnosis and intervention for children with ASD can help create an ASD-friendly environment that supports their communication and social interactions skills (Fennell, Eriksson & Gillberg, 2013).

d. Trustworthy shadow aides

Unavoidably, autistic children may encounter problems in pursuing class routines, learning skills in class, and interacting with teachers and peers. These skills, more often than not, are impossible to be self-learned in a short period of time. The children need extra training and coaching. Here it is essential for them to have shadow teachers or aides to help them set and achieve individualised goals and also help them integrate into mainstream schools.

The fathers interviewed in this study also declare that it is necessary to have shadow aides for their children. A shadow aide is an individual who is specialised in helping children with additional needs in a classroom. Shadow aides will need to have a particular level of knowledge about a child's diagnosis to be able to assist the child at school.

"There should be a shadow aide to help the child in class ..." (Mr. Akram)

"... Autistic children will need a shadow aide. They must have one. We, parents will hire shadow aides ..." (Mr. Khir).

"To me, shadow aides definitely help ... but it should be long enough" (Mr. Amir).

According to Panirsheelum (2013), a psychology graduate, a member of the British Psychological Society, a child therapist, a shadow-aide, and a director of a company dealing

with children with special needs, shadow aides is one of the important things that a child needs before joining an inclusive education. Shadow aides would strive for ASD children to attain their greatest potential and would aim for the children to be independent and self-reliant within the community.

e. Enhanced Parents – Teachers Communication

It has been established that parents and guardians are key people in children's education, especially with regard to school learning. This is even more so for autistic children whereby there must be a connection between school and the home. This is also conveyed by the fathers in this study who said,

“I feel that a major problem is the lack of communication with parents. That means we don't know our child's development. We don't know what our child did today, the activities ... sometimes schools are very rigid. When we send our child, the grill is closed, parents cannot mingle, cannot go inside. It seems there's a border” (Mr. Akram).

“Yesterday, my wife went to the parent-teacher meeting. The teacher said that my son can already write. I have never seen him writing ... I wonder – can he really write? Perhaps, the communication between teacher and parents can be more often ...” (Mr. Amir).

If there is some kind of communication with the teacher. For example, if the teacher asks my child to recite a surah, at home I can ask him to read and reread the surah” (Mr. Khir).

The hopes expressed by the fathers substantiate findings from previous studies that show the quality of school-family relationships is critical in promoting positive outcomes and ensuring student success (Bibby, Eikeseth, Martin, Mudford, & Reeves, 2002; Glueck & Reschly, 2014). Therefore, it is vital to safeguard and preserve the decent rapport of home and school so as to guarantee the reciprocal connections between the two.

f. Reliable System

The fathers in this study also voice their hopes in relation to the system itself. They wish the education for their special child is properly overseen and taken care of. This includes the value of what they have paid for,

“As for me, I'm paying more than one thousand a month for a school with specific therapy. I hope everything is inclusive at that school, so I don't have to fork out extra money. That's my hope. I'm also observing the service and outcome – see how it goes ...” (Mr. Amir).

The dads also highlight their concerns about their son's social and educational development. They hope that there is a holistic approach, gearing the child to be able to lead a better life among the society.

“... I want him to be ok socially. Education too because when I’m no longer around, nobody else will take care of him. He will have to be independent. I think I need a holistic system – at least if 50% achieved – that’s good enough already” (Mr. Khir).

“... they have to be given equal chance to succeed together with normal children” (Mr. Amir)

One father mentioned that some good centres have managed to accommodate the needs of autistic children. At the centres, the children advance wonderfully in terms of learning, but when they join the normal or mainstream school, they do ‘easier’ and simpler things, which show a regressive development.

“If we can look at good centres so that we can follow the good ways. Because now I see that some children are doing additions, subtractions – they are forward. But when they join school, they just do activities like colouring, connecting dots – like they are going backwards. That’s not right, to me, right?” (Mr. Khir).

With a more flexible yet convincing school system and structure, autistic children can be better coached and taught. Perhaps, in meeting the demand of special needs children in the education system, students too should together be involved in the development of the educational system. This is because it gives them a sense of ownership and responsibility for the process (Ontario Ministry of Education, 2007).

g. Reviewed Policy

One more theme that comes to light is regarding the policy. All the fathers in this study agree that the special education scenario in Malaysia is much better now. It is gaining more serious attention from many parties (Chong & Graham, 2016). Nevertheless, the dads believe that some policies can be improved. Here are some ideas and notions presented by the dads, *“I personally think that they should relook at the policy. For example, if we want to treat a child about his or her learning, we have to treat properly on the learning aspects. So, there shouldn’t be too many ... we can mix. No problem. But if we mix, we need to consider whether the child is high or low functioning. If we mix simply mix all, it will be problematic. So, there should be a division between the high and low functioning groups – high in one group, low in another group” (Mr. Akram).*

“The curriculum is different; it will not be the same. We may have one standardised curriculum. But from the assessment angle, it will be different. Now, teachers in our special education system, we have RPI (Rancangan Pendidikan Individu) [Individualised Teaching Plan]. But as far as I’m sending my son to school, there don’t seem to be any. This RPI actually will be discussed with the teacher – how do you want your child to learn or gain? The teacher will make a plan as agreed together. Teachers and parents should both agree for the child’s education” (Mr. Amir).

“Our system is quite good already. It’s just how far the implementation is carried out. Now, the issue is the red tapes – there are many layers – the ‘nazir’ [school inspectorate], school

administrators and many others. At PPKI (special education classes), there are even many issues. For example, the good thing about a school for the blinds – it's specific for the blinds. But now, they want to mix – the blinds, the deaf, learning disabilities. So, I said – Allahuakbar, how is it going to be ... To me, I personally disagree. The children need specialised teachers. The blinds will need a specialist in teaching the blinds, and so on ...” (Mr. Akram).

“When the previous Education Minister announced about zero-reject policy, the centre (that I'm sending my son) has started to accept students other than autism, like cerebral palsy. They are taking in others, not only autistic children. But the policy should be expanded quickly ...” (Mr. Khir).

Apart from the ones mentioned, Mr. Akram also raises the matter regarding courses for parents themselves.

“Parents should also have courses. If we look at the pre-marital course, there is no specific module which tackle the preparation for parents if they are granted special children – how to handle this kind of dilemma” (Mr. Akram).

This corroborates with a study by Shin et al. (2020), which looked into the challenges faced by Malaysian parents with ASD and suggested that training for parents to support their ASD child is critical in reducing the difficulties that parents face. Thus, the policy-related issues raised by fathers in this study can be used to shape and guide future interventions by healthcare, education professionals, and policymakers to tailor to the needs of special parents.

Conclusion

The article reviews past related studies on parents' expectations in general, in the global and Malaysian contexts as well as parents' and fathers' expectations towards schools in the Malaysian context and abroad. It also depicts the methodology, data analysis and enumerate the main findings of the study. The delineation of stories about the fathers' experience with their ASD children has caused seven themes to emerge namely enriched teacher training programmes, practical teaching strategies for ASD children, autism-friendly school atmosphere and amenities, shadow aides, enhanced parents – teachers communication, trustworthy and reliable system, and reviewed policy. By examining the expectations in depth, the article could shed some light into the less heard voices of fathers raising ASD children.

Moving from here, conceivably some proactive measures could be taken into consideration. The schools could create a more progressive circle by bringing in extra parental involvement into their administration. Schools could also build positive partnerships with various parties to obtain help in providing the best facilities and expertise for their ASD students. Apart from that, training programmes for special teachers should be enhanced to ensure the best teaching pedagogy for the special children.

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