

Parental Perceptions, Attitudes and Involvement in Interventions for Autism Spectrum Disorders in Sarawak, Malaysia

Jing Xin Teo^{1*}, Bee Theng Lau¹

1. Swinburne University of Technology, Sarawak Campus, Malaysia

ABSTRACT

Purpose: *This study explores and compares perspectives of educators and parents regarding interventions used in managing Autism Spectrum Disorder (ASD) in Sarawak, Malaysia. Information on parental desires and limitations when selecting and maintaining management will aid in the development of strategies for ASD educators to work effectively with parents and caregivers, and vice versa.*

Method: *This qualitative research employed traditional question and answer interviews with 7 ASD educators and 30 parents. Interviews were semi-structured and questions were open-ended to allow for additional details to be relayed within the scope of the subject matter. Thematic analysis revealed overarching perceptions concerning parental attitudes towards involvement in their children's interventions, and implications of cultural context.*

Results: *Perspectives were similar regarding the importance of confidentiality from educators and cultural factors playing a major role in content of intervention chosen by parents. Perspectives differed across four themes. Of significance was the way in which both samples viewed parental self-reliance in supplementing interventions and parental attitudes in effort and perseverance.*

Conclusion: *Parental resources and culture influence ability and attitudes towards involvement. While educators may not agree on certain aspects, mutual appreciation of differing perspectives would benefit the children.*

Limitations: *Due to the lack of ASD service providers in the region as well as cultural reservations, sample size of educators and parents was small. The sample of parents is not typical of parents coping with ASD in the region.*

* **Corresponding Author:** Jing Xin Teo, PhD Candidate, Faculty of Engineering, Computing and Science, Swinburne University of Technology, Sarawak Campus, Malaysia. Email: jxteo@swinburne.edu.my

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INTRODUCTION

Awareness and understanding of ASD is lacking in developing countries (Al-Sharbati et al, 2013; Low & Zailan, 2016). This may be due to the poor infrastructure, dearth of practitioners, overall lower education levels, stigma associated with disability, traditional parental roles in child rearing, underlying cultural elements, and competition for resources in national spending (Rahbar et al, 2010; Wang et al, 2013; Tait et al, 2015; Heys et al, 2016; Blake et al, 2017). Faced with these hurdles, parents find it challenging to obtain resources, support, and maintain motivation throughout the long years of educating a child with ASD. For educators working in ASD amelioration, these factors can have a major impact on proper intervention application and success.

Need for the Study in Sarawak, Malaysia

Sarawak is the fourth most populous state in Malaysia with 2.65 million inhabitants, 58% of whom reside in urban areas (JPM - Jabatan Perangkaan Malaysia, 2015). There are only 7 known intervention centres for children with ASD in Sarawak, and these are located in the main cities. It was found that admission ranged from 20 to 150 students per establishment. With ASD incidence being as high as 1 in every 68 children (Christensen, 2016), there is an immense gap between available services and need. Despite conducting a rigorous academic database search, the researchers were unable to find any published studies originating from Malaysia which investigate educators' or parents' perceptions of ASD interventions.

Objective

To facilitate effective cooperation in running ASD interventions and programmes, educators and parents need to find some common ground. The main aims of this study were therefore to:

1. Investigate educators' perspectives of parental attitudes towards ASD intervention.
2. Investigate parental attitudes towards ASD intervention from their own perspectives.
3. Compare similarities and differences in perspectives in order to detect gaps.

METHOD

Research Design

The study employed a qualitative research design, with a semi-structured, topic-centred interview approach.

Participants

The 37 study participants consisted of educators working with ASD, and parents of children with ASD. Educators were approached by contacting ASD intervention centres, and 7 of them were interviewed. Parents were recruited through an advertisement for participation in a project involving creative-based intervention for children with ASD, which was a larger mid-term experiment the researchers were concurrently working on. The multilingual advertisement was sent to ASD education centres in a major city in Sarawak. If both parents showed up at the interviews, they were regarded as one parental unit. Thirty parental units or “parents” agreed to be interviewed.

Inclusion Criteria

Educators had to be from an institution licensed by the state government to carry out special needs services. Also, educators had to be in charge of the day-to-day running of their respective centres.

Parents had to be the parent or primary caregiver of a child between the ages of 5 and 12 who had been officially diagnosed with ASD.

Informed Consent

Participation was voluntary and uncompensated. Informed consent was recorded before starting the interviews. Participants were told that no personal or place names would be referred to, should any data be used in published materials. No identifiers pointing to the children, their parents, the educators, or place of work would be used as well. Participants had the right to stop the interview at any time and withdraw consent should they wish to do so.

Ethical clearance was obtained by Swinburne University, Sarawak Campus, and Swinburne University, Melbourne (2017/012).

Data Collection

Data collection took place by means of face-to-face interviews in a private room. Approximately 30 minutes were allocated for each interview. Participants were asked 10 open-ended questions to probe personal and perceived feelings of others. They were free to elaborate on their answers. This helped to reveal community attitudes and societal values at large regarding ASD. Questions were aimed at discovering what parents found most challenging about their situation with their child with ASD, the most pressing matters they were working towards improving, and what they wished to achieve through participating in the creative intervention project. Finally, if they wished to, parents were invited to share more about their child as an individual.

Due to sensitivities in this region regarding the subject matter and personal privacy, no demographic information was collected as regards participant ethnicity, religion, education level, marital status, or income.

Data Analysis

Thematic analysis as described by Thomas and Harden (2008) was used to synthesise and analyse the data. This consisted of three stages:

Stage 1

Interviews were typed out on word documents, then imported into QDA Miner Lite, a computer- assisted qualitative text analysis software.

Stage 2

Researchers determined and defined topics and sub-topics, then went through the text and dragged and dropped text segments into these headings, organising them according to meaning and content. This facilitated the emergence of major and recurring themes. Codes were reviewed and refined. Flexibility was employed by allowing new themes to naturally occur (Braun & Clarke, 2006). When codes at times overlapped topics, the researchers merged themes to improve strength of analysis by focussing on main ideas and concepts (Javadi & Zarea, 2016).

Stage 3

Once the researchers arrived at a consensus on the most important descriptive themes, the information making up the themes was used to resolve the objectives.

RESULTS

Explicit themes emerged from the codes – four of them reflected differing perspectives between samples and two reflected similar perspectives.

Table 1: Differing Perspectives between Educators and Parents

THEME DEVELOPED	Time spent actively involved in child's ASD interventions	Financial burden of ASD interventions	The necessity of self-reliance in developing/under-resourced countries	Parental attitudes are the single most influential factor in intervention success
OBJECTIVES	Summary of majority consensus within sample			
Educators' perspectives of parental attitudes towards ASD intervention	<ul style="list-style-type: none"> Parents need to spend more time actively involved in their children's daily intervention and overall educational programmes, although the majority does not. 	<ul style="list-style-type: none"> Parents face a significant financial burden in attempting to provide basic intervention for their children. Parents should learn and administer intervention to manage costs. 	<ul style="list-style-type: none"> Parents need to be self-reliant in terms of supplementing basic and limited intervention that educators can offer. 	<ul style="list-style-type: none"> There is an element of learned helplessness seen in most parents. Many believe that there is little they, the educators, or interventions can do for their children. This attitude results in self-fulfilling prophecy.
Parents' attitudes towards ASD intervention from their own perspectives	<ul style="list-style-type: none"> Parents would like to spend more time actively involved in their children's daily intervention and overall educational programme. Most are unable to do so due to time constraints such as work, childcare, and other responsibilities. 	<ul style="list-style-type: none"> Parents face a significant financial burden in attempting to provide beyond basic interventions for their children. Nevertheless, parents are willing to pay to try novel or multiple interventions. 	<ul style="list-style-type: none"> Parents are highly self-reliant in terms of supplementing basic and limited intervention that educators can offer. Own online research acts as a major source of knowledge and learning in terms of existing interventions and their applications. 	<ul style="list-style-type: none"> Parents are driven and determined to strive towards their child's improvement. Parental involvement in intervention is very important and prominent.
	Summary of comparisons between samples			
Comparison of perspectives	<ul style="list-style-type: none"> Educators understand the burden and lack of these resources, but feel strongly that most parents do not put in enough time in their child's intervention. Parents make a clear distinction between willingness versus the ability to do so. 		<ul style="list-style-type: none"> Opinions of educators and parents are on opposite ends regarding parental effort and persistence. 	

Table 2: Similar Perspectives between Educators and Parents

OBJECTIVES	THEME DEVELOPED	Protection of privacy and confidentiality surrounding ASD	Cultural factors determine what aspects are most valued in ASD interventions
	Summary of majority consensus within sample		
Educators' perspectives of parental attitudes towards ASD intervention	<ul style="list-style-type: none"> • 'Special needs', in general, is a very sensitive subject due to negative public perceptions and potential embarrassment. • Most parents avoid photography and videos of their child during sessions/classes. 	<ul style="list-style-type: none"> • Chinese parents place emphasis on academic learning above all else. • The demand for intervention to focus on this aspect is apparent. 	
Parents' attitudes towards ASD intervention from their own perspectives	<ul style="list-style-type: none"> • Confidentiality is extremely important when considering programmes and educators. • Parents believe that negative public perceptions may result in their child being treated poorly. • Parents avoid photography and videos of their child with ASD during sessions/classes. 	<ul style="list-style-type: none"> • Parents place major emphasis on academic learning, and their child's happiness. • Non-academic or creative interventions are valuable if they can encourage academic focus. 	
Summary of comparisons between samples			
Comparison of perspectives	<ul style="list-style-type: none"> • Educators have a clear understanding of parental perceptions involving the need for privacy. 	<ul style="list-style-type: none"> • Both perspectives strongly suggest that improving academic ability is the single most important goal of intervention for parents. 	

Time Spent on Active Involvement in Children's ASD Interventions

All educators and parents agreed that being short on time is the typical parental experience. This makes it difficult to get actively involved in their child's intervention sessions.

Educator: *"We can't expect so much. They are always busy - working, other children... a parent who is coming here is already committed."*

Educator: *"If you want them to do (extra) work at home and spend time with their children, then it is very hard. They have a lot of things - work, other siblings."*

Among the parents, 90% noted that their jobs and other children were the main reasons, and 74% of them reported feeling guilty that they were unable to be more involved.

Parent: *"We both work, so we really need to organise between ourselves exactly how we are going to send Alex (name changed) to his classes here and there."*

Parent: *"I work a lot, weekends as well... my wife works too...she has to take a lot of work home. Somemore (additionally), she's also always busy with our other two. I wish I could spend more time with Jimmy (name changed), teaching him, helping him learn. I feel really guilty that I can't."*

It would seem that packed schedules are the norm, as children are involved in a multitude of after-school activities throughout the week. 97% of parents reported extra-curricular activities outside of school and primary intervention. This ranged from other therapies to academic tuitions (after-school extra classes to help in exams), to music and sports.

Parent: *"Saturday is scouts, then swimming and speech in the afternoon. Sunday is piano and after that, drums. He has 2 hours free on Sunday after that, so we can only take part if it is on Sunday."*

Educator: *"I have parents that go to play group, speech therapy, Sunday school, swimming, tuition and so on, so forth. So, I would say taking part in 3 afternoons (of intervention) is already considered very committed."*

Five of the seven educators shared the opinion that a means of managing the severe lack of time to facilitate intervention involvement was for one parent to stay at home, at least temporarily.

Educator: *"We need to educate the parents that you need to put down your job and concentrate on the children. But most people here are working class...they don't have the time..."*

Financial Burden of ASD Interventions

The financial burden of ASD interventions was mentioned as a major issue by 97% of parents and 86% of educators.

Educator: *"Not many parents come from rich backgrounds...some are so hard up that we even have to try our best to help, which is tough for us as a non-profit. We can't afford to keep paying fees for everybody."*

While educators found that even basic intervention was often unaffordable for many parents, the interviewed parents established that finances would still take a noticeable blow, even for those considered affluent. Two parents demonstrated how their financial means determined the type, quality, and setting of intervention chosen:

Parent: *“Not including the private school...just the ABA, speech, OT (occupational therapy), music therapy, art therapy - I will try whatever there is if it might help – Aiyoh (expression of difficulty or pain), I think I spend at least 3800 to 5000 a month! For some people, that’s maybe five months gaji (salary)!”*

Parent: *“We go to Singapore a lot for ABA. If I’m in England or Australia, David (name changed) does a lot of sessions there too. But it’s so expensive! So, not realistic.”*

While all educators advocated getting involved in intervention, more than half (57%) noted that there were financial benefits in doing so.

Educator: *“EIP (Early Intervention Programme) is expensive. Parents should learn interventions to cut costs, but only a very small percentage is motivated to work with their children at home.”*

Necessity of Self-reliance in Supplementing Intervention

All educators stressed that children would eventually need to leave the centres, either due to age or sufficient progress. As such, they tried to push parents towards self-reliance in working towards closing the gap of service.

Educator: *“We want to work harder and get more from parents and their partnership, and we know we can only be there for a few years. After that, they are very much on their own.”*

Educator: *“Those children who are OK enough to go with their parents, then we don’t allow them to come already... because if they have a place to go they won’t do anything themselves.”*

Some educators sensed hesitation in trying new interventions, ASD management techniques, or accepting new information.

Educator: *“We really try hard to discover new ways to help the autistic children. If there is new thing and we tell some parents, they just smile at me and are not interested. They say they don’t dare to try.”*

Two educators explained that this hesitation or fear might be explained by the difference in mentality between people in smaller towns and those in bigger cities. Both mentioned Kuala Lumpur (the Malaysian capital city) to illustrate this contrast while describing Sarawakian culture as *“kampung”* (rural or small village).

Educator: *“In West Malaysia, I was surprised that so many parents dare to speak out. In Sarawak, we don’t discuss issues. Parents don’t have enough awareness. They don’t realise how much they can learn for their children. We have kampung mentality.”*

Educator: *“The KL side - they are more open. They will try new things. Research. Discover. Here in Sarawak we are still in a sort of kampung culture.”*

A majority of the parents interviewed (83%) however, expressed considerable interest in learning about ASD interventions and new or significant studies released by the media concerning the condition. All pointed to the Internet as their main source of ASD research.

Parent: *“I research a lot on the Internet... all the types of ways we can try to cure or reverse autism...we do the bio-organic diet, gluten-free, we cut out sugar.”*

Parent: *“I googled how to deal with her tantrums, her meltdowns - how to stop her from banging her head first, so she doesn’t hurt herself, and then giving her time to calm down by herself.”*

Unfortunately, this did not always have favourable consequences, as one father recounted:

Parent: *“I found this exercise and relaxation programme online, by an Australian company. Supposed to be really good for autism. It cost us something like 20,000, but we found that it seems not suitable for Ryan (name changed). And they say they support you, but how to support from so far? In the end we don’t use it.”*

Parental Attitudes are the Single Most Influential Factor in Intervention Success

All educators agreed that while perseverance and positivity were minimal, those parents who did have these attitudes were rewarded with noticeable progress.

Educator: *“When parents are very involved we can see very fast progress. Unfortunately, majority of parents play the role of driver and sit in the car checking their handphones (mobile phones).”*

Educator: *“A minority will do a little bit at home. Not many. But in these we see the difference, you can see improvement so much faster. The hardworking ones - the kids are so much better.”*

In contrast, lack of cooperation with educators meant that children would miss out on other often free or low-cost extra interventions.

Educator: *"I certainly cannot say all the parents will cooperate. Even though we ask them to come to the centre, they won't bother. They just promise and say, 'I will come', then don't come. That's one of the sad things about the parents here."*

Educator: *"When they come to interview we tell them the things they must do and to cooperate with teachers. 'Oh, yes, yes, yes'. But the minute the child is admitted to the school, it stops."*

At times, this would jeopardise existing intervention programmes.

Educator: *"Simple things like toilet training you need cooperation from the parents. You can't wear diapers at home and then don't wear diapers at school. So sometimes toilet training programme is not successful because for the child it's very confusing."*

Two educators explained that this negative attitude might come from a sense of division of labour.

Educator: *"They just leave it to the school – 'my child comes to study, so that's your job'. Do whatever you want to do."*

Educator: *"I already paid. I already sent my kid. I already did a lot. You go train them."*

All educators also recognised that a sense of learned helplessness could often lead to parents "giving-up" on their child and experiencing feelings of defeat and failure. This could be disastrous for chances of success at intervention.

Educator: *"Once you have an autistic child, the progress or improvement is very dim. That's the general perception, this feeling of 'lost cause'."*

Educator: *"A lot of teachers in this field are not well trained so when there is no progress they blame the children. As a result parents also have low expectations...the outcome is they do not want to do much more because there's no point – 'I'm wasting my time'."*

Educator: *" 'Never mind', just, 'tak apalah' (it doesn't matter)", 'nantilah' (later). They don't see the point anymore and we can't force them."*

Almost all parents interviewed (93%) expressed a determination and persistence which, although very different from the educators' typical experience, was similar to parents in the minority "hard-working" category, previously mentioned.

Parent: *"We do interoention with him every single day. We take turns. That way, he can have full-time ABA and some sort like play therapy."*

Parent: *"I stopped working so I can spend whole day with Evan (name changed)... My husband also, never-give-up type. Any therapy, he also want to learn! We actually speaking Chinese, but because all the ABA is English, so we learn English and speak English at home, don't care."*

Parent: *"We did flash cards...when you believe in it faithfully, every night, you come home, no matter how tired, and you work at it for days, weeks, months, years... You really have to stay focussed and dedicate that kind of time to him and don't allow anything to disturb it."*

Five educators touched upon ways to instil and encourage the correct attitude in parents. The consensus was to make it a point to educate parents, then show them the fruits of their labour.

Educator: *"If you want to see progress, you need to help parents engage and let them see that with their input, you can see your children grow and thrive."*

Protection of Privacy and Confidentiality surrounding ASD

All parents expressed the desire that educators should respect the privacy of their child and ensure confidentiality. Educators understood this concern and while some said that lack of awareness of ASD and traditional societal mindset may be why privacy is so important, none would go against parents' wishes in this case.

Educator: *"Majority, if not all, want privacy. Confidentiality. Especially the older ones are more private. This is across the board. All parents here."*

Some educators believed this stemmed from previous experiences of how socially frowned upon behaviours are viewed.

Educator: *"Even if we do counselling or family meetings or even let parents communicate amongst themselves to share feelings...I think they're very ashamed to speak about their children. Society makes them feel malu (ashamed)."*

Educator: *"Sarawakian culture can be very gossipy. When I tell you my problem, you gossip to others."*

As a result, throughout the course of intervention or even for research and service improvement purposes, recording images or videos of children for any reason were not condoned.

Educator: *"If we have visitors come and want to take photos, most Chinese and Iban will say 'no'. Maybe it's our upbringing. Maybe the public will think that ASD is very strange."*

Educator: *"Very few allow pictures. Usually no one allows video. And even if they do allow, they will ask you if you are using their children to do advertisement and make money for fundraising. They are very sensitive."*

On probing, parents admitted that public opinion was a factor, although it was the judgment of their own family and peers that carried the most weight in influencing this behaviour.

Parent: *"I don't like to post photos on Facebook. So, I don't like to join the classes that take a lot of photos and post everywhere, because none of my friends know."*

Parent: *"Until now my mother doesn't know. You know old people - she would say it's my fault."*

A real fear was that being too open about the condition would result in their children being ostracised. Again, culture was thought to play a role in this.

Educator: *"'Why your children like that?' Maybe my father or grandfather did something bad and now it comes back. Chinese and Iban believe this. 'Or you were pregnant and something happened?' Old people say things like this."*

Parent: *"Sometimes other children in school, you know kids - they will tease or laugh at him. Maybe their parents also don't understand. It's better if we don't say too much."*

Cultural Factors determine what is Most Valued in ASD Interventions

Both educators and parents agreed that culture determined the most desired areas to be concentrated on during intervention. An overwhelming number of educator responses seemed to link Chinese culture with the need for academic learning and improvement, even if it meant neglecting other important areas.

Educator: *"That's the problem with Asian families, they like it to be academic, particularly Chinese. 'How come my child still cannot do ABC?' 'How come my child still cannot read?' For them, that's the important thing even if we say your child can do independent self-care already. For other races, this may not be so."*

This observation was substantiated by parental responses on the matter.

Parent: *"Eye contact is not so important for the moment. But he is starting primary one (First Grade/ Standard 1) next year and still doesn't know his alphabet. This is our biggest concern."*

Parent: *"All the tests that come back, five marks, ten marks, zero marks - he needs to learn*

to sit still and focus on his studies, otherwise what will happen in the future?"

Chinese culture was also felt to be the reason why creative interventions may not be very popular with parents.

Educator: *"We only focus on ABA. We don't go to creative interventions because otherwise parents will say 'aiyoh, I pay so much and then they do only running around!"*

Educator: *"Our culture as Chinese...creative curriculum - singing, art, craft, music and movement has never been very emphasised. Even though I know children and adults would enjoy this."*

When parents were asked what they might be expecting from creative interventions however, a small majority (53%) had the idea that these interventions could be useful in improving focus in school or for homework.

Parent (mother): *"After exercising for around an hour, he can really sit down and pay attention in class. So, I thought something like dancing or sports would be really good for him."*

More parents (60%) were hoping that creative interventions might bring happiness and fun to their children's routines.

Parent: *"We brought her to a ballet class but...everybody kept looking...we didn't feel nice, like we were disturbing them. Because they would be all doing the same thing and then Sharon would be happily doing her own thing. A bit...paiseh (feeling of embarrassment). We didn't bring her back. But she was so happy so we kept looking."*

DISCUSSION

Results show that overlaps exist across themes and perspectives. The researchers made every effort to be inclusive and attempted to obtain random samples of parents. Despite not collecting demographic data, it was observed that most respondents in both samples seemed to be Chinese. It is not known whether this was due to more diagnoses of ASD occurring within this ethnicity, more practitioners working in the field, strong assistance-seeking behaviours for the well-being of their children as cultural traits, or the propensity for other cultures to be more accepting of ASD or disability. This could in part explain why responses pointed predominantly towards Chinese culture.

ASD Interventions within the Constraints of Time and Money

Time and money are universal worries in the realm of ASD amelioration (Sawyer et al, 2009; Frye, 2016; Burrell et al, 2017), more so in situations where there is no funding and user pays (Krakovich et al, 2016). As voiced by some parents, the need for time to create money in order to pay for intervention, results in not having time to spend with children during intervention. This vicious cycle also has repercussions for family time, which is thought to be highly beneficial for children with ASD (Kapp & Brown, 2011; Ferraioli et al, 2012; Amet, 2013). While some educators suggest giving up one job in exchange for home parenting, a loss of one income for a family struggling with the effects of ASD can be debilitating (Cidav et al, 2012). Rising costs of living in Malaysia mean more dual career families are emerging in order to make ends meet, even without the presence of disability (Bakar & Abdullah, 2013; Zaimah et al, 2013).

During the interviews, two respondents revealed that they were single parents. For them and others in similar situations, the constraints of time and money would be unmistakable (Jurado, 2005; Varin-Mignano, 2013; Dyches et al, 2015; Thakur & Varmani, 2015; Seepersad, 2016; Stebbins, 2016). Researchers and professionals need to focus on the development of intervention(s) of low or reasonable cost so that fewer sacrifices need to be made by other siblings, dependents and parents themselves. This in turn may cut down the need to exchange time for money. Initial studies, including those in rural areas and with travelling military families, have shown great promise of parent-as-interventionist models (Loughrey et al, 2014; Hampshire et al, 2015; Klin et al, 2015; Blake et al, 2017), while emerging research involving the use of telepractice to train or self-train parents in this regard contain compelling cost-saving elements which should be considered (Meadan, 2016; Neely et al, 2016).

Designing Interventions within a Cultural Context

Privacy and confidentiality about children and their families was an issue on which both parties saw eye-to-eye. Being stigmatised by the community is common in settings with low awareness, and results in anxiety regarding private details being leaked (Davidson & Henderson, 2010; Grinker et al, 2012; Kinnear et al, 2015; Tilahun et al, 2016). The parents' and educators' responses are illustrative of those from enmeshed cultures, often seen in the East. To avoid causing offence or strain in the extended family or peer group, the opinions of others are often taken on board or family members may not be told of the diagnosis (Wang et al,

2011). Confucian emphasis on saving face and respect for the older generation also means that many parents of children with ASD still need to comply with their own parents' points of view, even if they realise that they may be doing so at the expense of better alternatives (Yi & Lin, 2009; Nelson et al, 2012). Such frustrations can weigh heavily on the well-being of families.

While results showed that creative interventions were not considered as valuable as interventions such as ABA which were believed to be more academic, all but one of the parents reported that they had put their children into extra-curricular activities outside of school and interventions. Researchers in East Asian cultures explain this as parents' aspirations to achieve in competitive environments and accumulate cultural capital (Wu, 2011; Lu, 2014; Cheng & Kaplowitz, 2016). A point for researchers to consider would be the incorporation of academic learning and traditionally approved pursuits, such as music and sports, within ASD intervention in order to make them more attractive to parents.

Privacy is of utmost importance when developing any form of intervention. This translates to educators needing to employ sensitivity and prudence when it comes to public outings, play dates, and the way information is managed. While this is a far cry from the current movement of "owning" the condition as seen in developed nations (Cascio, 2012; Owren & Stenhammer, 2013; Powell & Acker, 2015), compliance by educators is crucial in order to cultivate trust. Re-educating parents about the merits of acceptance and tolerance needed for holistic intervention is a long journey in many Eastern cultures, as old ideas seep into and shape current ones. Although recent studies suggest that there is evidence that societal understanding is slowly emerging in developing countries (Wallace et al, 2012; Malcolm-Smith et al, 2013; Taha & Hussein, 2014), for now, one might surmise that going against the grain could do the children more harm than good.

Creating a Norm in Parental Attitudes towards ASD and its Amelioration

As regards parental attitudes and self-reliance, there was a noticeable gap between what educators observed and what parents reported. The presence of ASD in families can be extremely stressful and it is imperative to find ways to close the gap and achieve congruence between educators and parents for the child's progress, mental well-being of parents and therefore of the entire family.

Due to the nature of the sample selection process, it is assumed that parents who applied would have been self-motivated enough to do so. In this sense, there is

much to learn from them as they would most likely have comprised the successful examples of intervention mentioned by the educators. ASD literature upholds the finding that parental attitude is a robust predictor of outcome - above type of intervention, duration, and intensity - relative to the severity of the condition (Moore & Symons, 2011; Karst & Van Hecke, 2012; Narzisi et al, 2015; Pickles et al, 2016). The failure to follow through with programmes, frustration, and episodes of helplessness are not uncommon experiences for parents managing ASD (Moore & Symons, 2011; Weitlauf et al, 2012; McStay et al, 2013). It can be due to numerous and differing reasons, so each experience is unique and needs to be tackled individually until norms in parental attitudes are established in Sarawak. Creating and nurturing a culture of acknowledging the condition and its trials and tribulations, at least within the community of parents, will go a long way in providing empathy, support, and eventually the demand for associated services.

For now, the onus is on educators to continuously remind parents that effort equals results. Having said that, research does advise that due to etymological reasons, some interventions work exceedingly well for some children while some are found to have hardly any effect, and vice versa (Dempsey & Foreman, 2001; Vivanti et al, 2014). It can be recommended therefore that allowing a wider range of intervention options might bring more success and thus motivation to soldier on.

CONCLUSION

Results of the study suggest that educators in this field are well aware of the difficulties that parents face but are often unable to assist beyond the limitations of their role and available resources. The parent sample indicates that awareness of ASD and attitudes towards interventions are however changing established beliefs and the mentality of whole populations, whether they be ethnic, geographical or cultural, but it can take years. Time is always of the essence in ASD amelioration, hence educators and parents cannot and should not wait. ASD professionals and service providers working in these regions need to continue exploring reasons for resistance, in order to develop and share knowledge about culturally accepted interventions which can be applied swiftly for the benefit of the children.

Limitations

Due to the lack of ASD service providers and difficulty in accessing personal opinions and information from parents, both samples are very small and therefore

only able to relate a narrow viewpoint. Additionally, because the parent sample was obtained through a call for research, there is a disproportionate number of actively involved parents. To construct a more realistic picture of the situation at hand, the researchers would recommend developing means to gather further information from average parents who have children with ASD.

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