

Narrative from the Care Givers of Autism Spectrum Disorder Children in Malaysia

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Abstract. The paper adopts the lens of moral philosophy to take on a relational approach. Data was collected using qualitative methods of observation and interviews. The narratives drawn from the care givers of autism spectrum disorder children will be presented. The findings show a lack of awareness and understanding of children with autism spectrum disorder among the general public in Malaysia. The themes emerging from the narrative further support Eva Kittay's views on aspects of interdependent relations. Carers of autism spectrum disorder children yearn for acceptance of their children in the general community.

Keywords: Autism spectrum disorder, Autistic children in Malaysia, Interdependency, Human dignity.

1. Introduction

This paper adopts the lens of moral philosophy in a social context to examine the ways the caregivers or parent-child relationship are related to the public awareness and discrimination. In a world that divides normality and abnormality, autistic children are seen as disabled and problematic. The existing scholarship or discourse on disabilities stresses intervention and remedy, little attention being paid to understanding human interdependency.

In Malaysia, autistic children are classified as "Orang Kurang Upaya" (in Malay, meaning people less capable). As the terminology applies, it denotes a less capable person, and the term may extend to ascribing to a person less dignity and less respect. For classification purposes, it may be bureaucratically convenient when issuing a special identity card or social welfare. Autism, being classified as a disability, is intimately linked to a model of deficiency of impairment. Among the general public there is little knowledge about, or understand of autism. In Chinese the language is translated as a disease of 'loneliness'. In Taiwan, autistic children are described as 'Sons of Stars' meaning they are children from other planets whose language and inner worlds not known to us. This presents a picture of an unbreakable barrier between our world and theirs. Although the first study of autism was undertaken in 1943 by Leo Kanner [1], the world of autistic children and the experiences of their carers is not widely understood among the general public. Since the binary opposites division of a deficit model has come under attack [2], adopting a relational aspect to view this issue is an attempt to offer a better appreciation of the different abilities of human beings.

2. Literature Review

2.1. Relational Aspects in the Studies of Autism

Autism is known as complex development disability. Due to the impairment of the neurological function, autistic children display a spectrum of disorders which can be characterised by severe deficits in socialisation, communication, and repetitive or unusual behaviours [3]. Early identification is helpful for intervention, however, due to the highly genetic and multi-factorial nature of Autism spectrum disorders, there is no cure. The lifelong struggles of those caring for autistic children are aggravated by public ignorance and lack of understanding.

Moreover, studies of autism that adhered strongly to a medical model actually deepened the division between disability and non-disability which is largely a social construction. While applying diagnoses and interventions, it also strengthened biases and misrepresentation of disabilities, which resulted in people with

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disabilities being excluded from the mainstream of society. This combination of ignorance and prejudice among the general public severely challenges egalitarian theories of justice [4].

There are ample philosophical arguments drawing our attention to the dignity and moral status associated with personhood. If a person is incapable of rational deliberation it does not mean he/she is non-person and thus deserves no dignity. Kant proposed that autonomy is the basis of the dignity of human and of every rational nature [5]. This philosophy allows people who are cognitively disabled, incapable of autonomy but in need of protection, to be discriminated against and ascribed lesser status and poorer treatment than others. Therefore Martha Nussbaum [6] proposed that it was necessary to guarantee that people with cognitively disabilities be treated as citizen with equal dignity specifically in the areas of medical care and educational needs. The words “dignity” and “deserved” can be distinguish from the word “right”. Aristotelian justice appears to have no conception of ‘right’, which strictly adhere to the principle of universality by Kant that stresses on autonomy basis. According to Cara [7], everyone is considered to have a right be treated fairly and justly according to their particular needs. Failing to treat people as they deserve according to their needs, can be unjust to them and thus the concept of justice has a wider scope than that of rights. Thus each of the cognitively disabled people receives their “due” to be cared for in the light of (a particular) justice. In the same vein, Nussbaum [6] advocates a belief that public organisations, as part of the human community, need to empathize with the people who are unable to communicate, such as autistic children and their caregivers, to feel compassionate for their suffering.

Eva Kittay, whose daughter is severely cognitively disabled, has made an argument about the importance of social understanding and social support in parent-child relationships and her conclusion about the moral status with her daughter is: “the moral importance of the mother-daughter relationship is not an isolated personal relationship”. She has highlighted the interdependence of human nature in a social context. In this context she cannot care for her daughter as a mother if others do not respect her as a being worthy of the same care as is due to any child [8] Kittay therefore puts the relationship between the cognitively disabled and caregivers in a global and cosmopolitan perspective. She emphasises that human beings are interdependent as a whole, the ways we conceive of the care and obligations that fall upon caregiver derives from a wider context and are linked to the quality of life we believe people with cognitive disabilities are capable of having [9]. It means that this relational aspect between the community and the caregivers serves as a determining factor, either strengthening them in their task as a caregiver or diminishing their role as a useless effort spent on a being less than human.

Another much neglected aspect is the extent to which the cognitively disabled are capable of having a flourishing life on their own, and by interaction with their caregivers. Caregivers develop insights and caring skills from the relationship with their autistic children. Kittay [9] refutes the misconception that no multiply disabled individual can be described as “entirely unresponsive to their environment or other people.” As the emotional world of autistic children is still a mystery to most of us as we should not assume limits to what they are capable of but admit that our knowledge of their capabilities is limited [10].

2.2. Autism in Malaysia

According to government information, The National Autism Society of Malaysia (NASOM) [11] and many other private non-profitable organizations in Malaysia have been established to provide a range of help, care, support services and education for autistic children. Fourteen Early Intervention Programmes aim to help younger children towards a possible transition to normal stream education while three Vocational Programmes aim at teaching them to acquire basic life skills such as baking, food preparation, laundry, housekeeping services, sewing, handcrafts, data entry services and card making [11]. It is hoped that people who suffer from autism spectrum disorders are able to learn and lead a fruitful, productive and fulfilling life (About NASOM, n.d.) [12]. The behavioural approach is a common technique used for training and intervention [13,14]. Frequent Autism Awareness Campaigns are held to promote public awareness [11,12]. Autistic children are called ‘Anak Istimewa’(Special Child in Malay). However, there has been little study of the relational aspect between the caregivers and their children and how public views on autism affect this relationship. As with all of the disabled community, especially the cognitively disabled in the case of autistic people, their families must have fought a hard-won battle for

education and opportunities yet their voices are hardly heard. The aim of this paper is to give a voice to the caregivers.

3. Methodology

This is a qualitative study. Data was collected by two researchers and a group of students doing industrial attachment at an autistic organization in an urban area in Malaysia. Seven students who were attached to an autistic learning centre in Perak state, Malaysia, helped in doing observation through their daily interaction with the autistic children. They each ‘adopted’ one child and kept written records of the behaviour that child for the 4 months of their industrial attachment. The research participants were involved in the daily teaching and activities throughout the entire four months. Interviews were carried out with four parents and two teachers from the centre at the end of the industrial attachment. All the observations recorded about the children were compared to assess their progress. The interviews were transcribed and emerging themes were presented

4. Findings and Discussion

A few important themes emerged from this study. Among those whose behaviour is described as ‘weird but harmless’, unique ways of coping were found in the narratives of their caregivers.

4.1. My Child is Weird, but Harmless

A few carers prefer not to take their autistic children into public places because of the public reaction to them.

“I am taking care of two boys during weekdays (both 18 year old), they will go back to their parents during weekends. There was once I took them to a bank. They sat there quietly for just a while, then they made some noises. They normally have a short span of concentration, and they enjoy making noises. They feel secure doing it and they enjoy the sensation of it. Then people just moved away from them one by one...it was so obvious that the few benches of seats around them became empty...I feel that the people around were feeling scared and fearful of them. I shouted “they are Orang Kurang Upaya” (less capable people).

This caregiver, who was a retired teacher from an autistic training centre, shared her view that because of lack of understanding among the public, parents usually overprotect their special child while they were young and delay the necessary training as a consequence. Because of her experience working with autistic children she strongly encourages parents to expose their children to public situations so that they can generalize their learning in different environments and with different people.

Another parent described her experience of taking her 10 year old daughter to a supermarket. While at the top of the elevator, all of a sudden, her daughter adopted a ballet pose and she held that position for a few seconds. This parent spoke in a mixture of English and Malay. “I feel so malu”(Malu means shameful). The shame came about due to the difference between the behaviour of her child and other children. “she would suddenly raise her hand or make a claim, like the first time watching movie, she exclaimed ‘B-I-G, T-V-’ as if no around” the mother said she had got used to these unusual expressions but still she could not stand people staring at her.

“She is harmless, she is just different from other children but others don’t understand. They thought she is weird and I failed as a parent because I never taught my child how to behave.”

The experienced teacher from the centre shared that, some of them may behave oddly, slapping themselves, scratching their face, swinging their head, pulling their hair when they are upset or angry when their normal routine is disturbed. This shows that they have emotions. They are capable of feeling happy, anxious, upset and angry but they just do not know how to express themselves.

4.2. My Child is Capable of Feeling

One parent whose son is 18 years old gave examples of her child’s behaviour to show that he is capable of feelings.

“Normally he would laugh when other people fell down as he enjoys the sound of object falling down. But there was once his grandma fell down, he kept murmuring “Popo fell down, popo fell down” (Popo means grandmother in Cantonese) He did not laugh but he kept repeating ‘popo fell down’ until rescue came”...when he saw his friend who knew him since young cried. He said ‘No cry, Steven. No cry Steven.’ Although both of them knew each other since they were 4 year old as they both attended the same special school but they never communicate with each other. But whenever he gets something, he will make sure that Steven gets too, and Steven will do the same for him”

But some parents were less fortunate, “I am not sure if my son feels it, it is like keep knocking at a door without receiving any answer and I won’t know when he would answer me. I wish there is a bridge for me to walk into his world but I couldn’t find a way to do it. Sometimes I thought he doesn’t have emotion, but there were tears I observed from his eye.”

4.3. My Child is Unique though Less Capable

Parents whose child was less severely autistic (even though they used the term ‘less severe’ there is still no communication with others and the eye contact with people is less than a second. However the eye contact with his carer can last for two or three seconds the most) shared that their teenage child is capable of searching on a computer. One Chinese boy who is a cartoonist (10 years old) likes animals, especially horses, and would search the internet for different ways of drawing horses. A Malay 17 year old girl whose nickname is ‘staring girl’ would stare at the patterns on people’s clothing for long hours and she would memorize and draw out the patterns later. She was found to have stolen her teacher’s internet password by listening to the tapping of the keys. Her teacher later found that ‘staring girl’ had logged on to Facebook on her behalf and added many friends for her. It was amazing to recognize and memorize another person’s password by the sounds she heard. It is not the purpose of this paper to report the savant skills such as those shown in the film ‘Rain Man’ to perpetuate the negative or stereotypical expectations surrounding autistic children. However, the autistic children did show some unusual focus and unique skills.

4.4. I Want My Child to Know There is a an External World Outside

Outdoor activities such as shopping, are more than a necessary routine. It is in fact an important training aspect for autistic children. Teachers shared that the more that autistic children are exposed to public activities the better they could generalize their learning in other situations. And this training needs to be begun as early as possible for effective learning. Otherwise children develop rigid behaviours which are hard to change. The experiences of the teachers and the observations from the student observers confirm this. The teachers shared:

“This training serves both ways: for the children to get used to different environment other than their own home and the school (that is the centre), and also for the public to know that there exist this group of special children”

“My child will be excited to go to Tesco (one of the supermarkets in Malaysia). He would go to the CD shelves and search for the CD he wants. At the beginning he took all the CD down the shelves and made a mess of it. But slowly he learnt how to select his CD without making a mess. He even told me ‘this is less expensive’

“Going out is like giving a chance for them to expose their vulnerability to others. But I keep bring my child out. I don’t care how people stare at me, my child doesn’t bother either. I just want him to get used to there is a world outside there. Now he has learnt he could go out to take bus, to get the CD with cartoon...later, he may know there are other people outside...who knows?”

4.5. More Than Patience is Needed

The participant observers of this study note that most of the children in the autistic centre did not show much improvement for any of the behaviours under observation which included the initiation of play, energy expanded in play, types and content of play. Their concentration, stereotypical behaviours and perfectionism remained almost the same, especially among the older children. Only the younger children showed progress and improvement. It was observed that those children above the age of 10 were harder to change compared

to the 5 or 6 year olds, who were in a transitional class from which children who had been diagnosed early enough to benefit from specialised teaching were helped to integrate into mainstream

Among the older children, even with one-to-one intervention, very little improvement is shown. However, in vocational classes where older children learn cooking and crafts, stereotypical behaviours remained, the children were observed washing the rice slowly with a mechanical rhythm; cutting carrots to exact size and shape; taking hours to finish a little piece of sewing or knitting, but the patterns were done perfectly.

5. Conclusion

The best way to help autistic children is not to isolate them from society, but to draw them gradually into our world. Their mental doors seem to be locked and there may be no guarantee a key can be found. We need to be aware that they are special. Our treatment of them is the test of our humanity. The prevalent public view of autistic children as less capable, less dignified or less human, impacts on the lives of the caregivers weakening their confidence in their children and in themselves. By giving genuine understanding and empathy to the care givers, we show our support and return to them the dignity due to all parents and their children.

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