

Sharing a Diagnosis of Autism for your Child

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Parents of children who receive a diagnosis of autism for their child will inevitably, at some point, have to consider how open to be about the diagnosis. This may begin with the potentially challenging process of admitting the reality of the condition to themselves. Once this step is taken, it leads in turn to a succession of further decisions about how open to be, starting with the close and extended family, and moving on to friends, school and society in general, if not necessarily in that order. Then of course there is the question of if, when and how much to be open with the child themselves about their condition. The argument against openness in most cases would appear to revolve around feelings or fears of stigma and shame. Either families may themselves feel ashamed, or they wish to protect their child from such feelings within themselves or from others. In this article I will first consider what evidence exists in the available literature as to how pervasive such a culture of shame may or may not be in Japan, where I myself live. My family is English-Japanese bilingual and my son, who received his diagnosis around the age of four, has been educated within the Japanese public school system (Ryan, 2013). I will consider the various levels on which a choice about openness regarding an autism diagnosis is required, and look at this through the lens of the experience of my family and other families both within and outside of Japan, known to me either personally or through my research.

To examine shifts in Japanese attitudes towards autism, I consulted a 2004 paper entitled 'Attitudes of Japanese Adults towards Persons with Intellectual Disability: Comparisons over Time and Across Countries' (Tachibana & Watanabe, 2004). This study compared 3 surveys of elementary school parents in

Japan conducted at roughly 20 year intervals between 1960 and 2000. Firstly, it should be noted that the terms intellectual disability (ID) and ASD are not a precise match, since intellectual developmental delay is not a universal feature of autism across the spectrum. There may nonetheless be a tendency to blur or conflate ID and ASD given the relatively low level of awareness regarding autism in Japan, so this study may at least give insights into attitudes towards neurodiversity in that country.

The most recent of the surveys (2000) showed that attitudes towards people with intellectual disabilities (ID) had "improved greatly" (p.227) over time. Particular positive shifts were noted in the concept that children with ID needed special consideration and support. The biggest change of all was a greater acceptance of having children with ID sitting in "the next seat in school" (p.237). On the other hand, the researchers found that certain categories resisted this upward trend, in particular there was a noted resistance to the idea that people with ID should be open about their condition. In the comments section, several respondents explained that such openness could be damaging to the person and their family. One comment mentioned that the very existence of a younger sister with ID had been carefully suppressed by her family. Nor should such stories be readily dismissed as outliers, considering that it is "well known that the number of people with ID registered with local government for obtaining social services in Japan is much smaller than the actual numbers that would be expected" (p.233), which suggests that many families chose to conceal such a situation. If some families may have felt that an open diagnosis is to be avoided, this opinion was also shared,

if perhaps for different reasons, by Japanese scholars, who, prior to the introduction of formal special education services in 2007-8, publicly expressed fears that otherwise able children might endure stigmatization from the label of being “disabled” (Kayama & Haight, 2013, p.25). Overall then, the picture would appear to be one of a context of growing awareness and understanding, with however a marked reluctance to expose children or their families to the dangers of fixed labels or an open diagnosis.

In my own family’s case, I would say that so far we have not experienced negative attitudes so much as ignorance or a lack of awareness. I should qualify this by noting that there have occasionally been unkind words from our son’s peers, but given that such comments were made without specific awareness of his condition, I have assumed that they are not relevant for this question. In general, I have felt that there is less of an overt sense of shame in the U.K., where I am from, than in Japan, although it is difficult to be certain of people’s private thoughts. Among Western associates, I have found if anything a tendency to exaggerate the possibility of ‘genius’ or savant traits in autistic people. In Japan it feels like more of an issue to be public about autism, but asides from a lack of general awareness which tends in my personal experience to be more marked among older generations, I have not directly sensed any prejudice towards our son on account of his condition. I have however on many occasions witnessed parents struggling with openness on its various levels. This has come about both through personal contacts and also through my research. Regarding the latter, a key factor was the Facebook group *Bilingual Children with Developmental Differences* which I set up with the goal of sharing information and support between such families. Through managing this group, I got to talk to many parents around the world, particularly those struggling to cope with the initial shock of a diagnosis. I will refer to these sources to provide context for the various decisions regarding openness which were made by my own family.

As for opening our own minds to accepting the diagnosis, it is probably never an easy process, but it was less a struggle with denial than an anxiety about achieving clarity. Having had the chance to reflect and research the subject in depth in the several years since the diagnosis, I share the belief that rather than seeking

to conceal autism, or indeed to consider it an affliction, we should accept it as simply one of the more colourful strands of the ‘neurodiversity’ (Silberman, 2015) which describes the human condition. At the time however, the PDD-NOS (pervasive developmental disorder not otherwise specified) diagnosis we initially received seemed vague, and we also wanted to have our son tested in both of his languages before we could really get on board with it. I have corresponded with several parents who struggle with accepting the diagnosis for a time, particularly if their child does not conform to their preconceived notions of what an autistic child is like. In the case of my own family, we did not suspect the condition for some time for just such reasons. On a deeper level, there are those who champion the idea that autism is not an innate neurological condition, but that it has a ‘cause’ which can therefore be identified and eradicated. In its extreme form, such ideas are championed by the controversial British academic Andrew Wakefield, who still vigorously maintains that the incidence of autism is linked to vaccinations and gastrointestinal disease. The lure of such ideas may be the temptation for any parent to believe that their child is fundamentally ‘normal’, but is being affected by external factors such as vaccines or diet. While the idea that vaccines cause autism is both unfounded and harmful, medical advice suggests that experimentally removing certain foods from a child’s diet will not harm the child provided that a balanced and nutritious diet is maintained (Jordan, 2018). Given that certain parents have reported beneficial effects of avoiding certain food types, I can sympathise with parents I have met who adopt a ‘Why not?’ approach to testing various treatments of this sort.

As for sharing the diagnosis with our wider family, we were fortunate enough not to encounter any resistance to accepting it. The limit of our struggle in this sense was simply that everybody in the family, including ourselves, started out not knowing much about what autism was in general, or how best to help our son in particular. It took time for this to improve. I have however talked to one parent whose mother forcefully rejected the label from the outset, as though to accept it implied a lack of love or belief in the child.

The question of whether to be open about a diagnosis beyond close family and friends is very complex. I have found it to be a common occurrence in

Japan that parents limit the public disclosure of an autistic diagnosis, presumably to protect the child from being stigmatized. The parents in such cases do not always agree on what policy to adopt, which may create tension within the family. Both personally and professionally I have also met families where it was considered by the parents to be in the best interests of the child not to reveal the diagnosis to the child themselves. In my work as a teacher, it can happen that a parent wishes me to know the developmental condition of a student, but does not wish for the student to be told. Sometimes a family may be open with the child about the existence of some sort of issue, while avoiding mentioning the word autism, with its attendant stigma. In my experience this has included utilizing the publicly available therapy for their child, including the use of medication, while ascribing the reason for such treatment to some other factor.

In the case of my own family, the principle issues involved have been when and how to explain to our children about the condition, and secondly how rigorously the right of the child to privacy regarding their condition needs to be protected. Regarding the former question, it has been our policy to be open about the diagnosis from an early age. Our goal, imperfectly realized, was through dialogue with our son to try to focus on the positives of his condition in terms of his strengths, while trying to be realistic about the challenges he faces, such as with concentration or loud noises, in order to help him prepare to deal with these eventualities. We were very anxious that this kind of talk might be upsetting for him, but in the event his no fuss response encouraged us to feel that it was not necessary to impress upon him that this was a 'big deal', and to opt for a more relaxed, matter-of-fact approach, a style which appears to have also been effective for other parents (Rothman, 2013). I was recently advised by a neuropsychologist that it is important to express to the child that autism is something they have, rather than something they are. It seems that the latter course can lead to some children identifying as autistic to the extent that they may feel that treatment is a threat to this identity. Given that our son has not expressed to us how he feels about being on the spectrum, in some ways it is too early to say if we have made the right choice on his behalf. As far as we can see however, it has been useful to be able to communicate with him about how to

negotiate challenging situations resulting from the condition.

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