Socio-Cultural Support for Children with Autistic Disorders and Their Families: Japanese and Australian Contexts

Poon Lung Ku, Macquarie University, NSW, Australia
Mio Bryce, Macquarie University, NSW, Australia

Abstract It is not uncommon to find autism among young children. Autism is a spectrum disorder with various labels such as Asperger's Syndrome and Pervasive Developmental Disorder, and can be classified as mild, moderate, severe and high functioning. Despite the fact that it covers a range of different diagnostic terms, children with autism have impairments in social awareness and interaction. Social ability is crucial in order to cope with everyday life. These children need assistance in learning communication skills so as to get along with others, especially their peers. Methods and styles of interaction and social support provided may vary between cultures and environments. This paper will investigate the socio-cultural contexts of children with autism and the support provided for them both in Japan and Australia, as well as identifying possible cultural hindrances to successful intervention strategies. Moreover, autism does not merely affect the child. It can mean chronic stress for the entire family. Family support advocated in both countries will also be discussed.

Keywords: Autistic Spectrum Disorder (ASD), Social, Cultural, Interventions, Family Support, Japan, Australia

Introduction

AUTISM OR AUTISM Spectrum Disorder (hereafter ASD) is a life-long neurodevelopment disorder. The causes, mechanism and treatment of ASD have not yet been articulated, although early educational intervention is believed to be effective. ASD is elusive, complex and often misunderstood as it is characterised by widely varying degrees of impairment in communication skills and social interactions, and in restricted, repetitive patterns of behaviour (The World Health Organization, 2009). Having a young brother with severe ASD, Stacy Clifford urges us to realise the profound intricacy of ASD, stating, "autism challenges our concept of being human as an autonomous, self-determining rational agent" (2006, p. 15). The seriousness of ASD and the inadequacy of social awareness and support were finally recognised globally when World Autism Awareness Day (WAAD) on 2 April began to be held from 2008, as one of only three official disease-specific United Nations Days.

ASD is generally found at around 18 months, often with noticeable decline, even retraction, in their linguistic and behavioural development. It is extremely difficult to acquire any accurate data on the occurrences of ASD, due to the scarcity of comparable data and the reliance on behavioural diagnoses and widely varied symptoms and intensity, although the number of people with the diagnosis is estimated to be 0.6-1% of the total population (e.g., Newschaffer, et al., 2006). Around 80% of those with ASD are males (Fombonne, 2005).
A rapid rise in prevalence has been observed globally in recent years (e.g., Morbidity and Mortality Weekly Report, 2007), however, that may partially be because of an increase of awareness and the establishment of diagnostic procedures.

The word `autism` was first used by Leo Kanner in 1943 to identify people with severe autism, however, it is also called `ASD`, for the conditions vary widely without definite distinction between one subgroup and another. Autism can be classified differently as mild, moderate, severe and high functioning, and labelled Asperger’s Syndrome or Pervasive Developmental Disorder (Roe, 2001). On the one end of the spectrum, there is low functioning autism or severe autism, often with multiple disabilities such as in language acquisition. On the other end of the spectrum, there are people with high functioning autism or Asperger’s Syndrome, who have an average or higher IQ, language acquisition and an absence of physical impairment. Although very rare, there are also people who have severe physical and/or mental handicaps, yet with extraordinary capacities in narrowly specified areas, such as calculation or photographic memories. With such astonishing mismatches in abilities, this is called Savant syndrome, derived from Langdon Down’s terms from 1877 to describe people who have “extraordinary memory but with a great defect in reasoning power” (quoted by Hill, 2001), and exemplified by the main character, Raymond Babbitt, played by Dustin Hoffman in the movie *Rain Man* (1988) (Hill, 2001). Recently the diagnosis of ASD has been broadened and become more detailed, with insufficient professional consensus about the distinction between the abovementioned subgroups. It is feasible that in years to come, the term ‘autism’ may be replaced by several terms to differentiate the characteristics of the disabilities. Nevertheless, children with ASD share the same difficulties in social interaction, often being inflexible, hypersensitive and unable to ‘imagine’ and connect things to make sense and use language in culturally appropriate contexts.

One of the serious difficulties of ASD lies in the core disposition of autism—an intensive and exclusive focus on self, that is however, totally unintentional. In *Nobody Nowhere*, Donna Williams, an Australian author with ASD, provides an invaluable insight into an autistic person’s perception and experience and how they are vastly different from those of the people around her. In her first dream and the following frequent daydreams, in her autistic world, she is alone and happy, whilst walking through an entirely white sphere, being fascinated by numerous pastel coloured circles floating and twinkling around her. Humans, including her family members, are recognized as threatening foreign objects (e.g., rubbish, shadows or just hands to hit her). Her happiness in her own self-contained world is in stark contrast to her fear and incomprehensibility of the external world as well as others’ negative views of her ‘deviant’ behaviours. Such characteristics frequently prevent the social inclusion of individuals with ASD, for they tend to refuse to do things ‘our way’ (Crouch, 2002).

The self-containment of individuals with ASD causes heartbreaking hardships for caregivers, especially their mothers, more so than for children with ASD, as it may well prevent their natural nurturing of a mutual, affectionate bond and communication. For example, a mother depicted her daughter, “It was really tough, you know. She was unloving, unaffectionate” (quoted in Jilley, forthcoming). This is why Marshall and Long argue, “few disorders in children pose a greater threat to the psychosocial well-being of parents than autism” (2010, p 105). Family involvement is the primary and necessary element to support children with ASD, however, stress, fear, anxiety and worry in families is often chronic. As stated by the The Secretary General of the United Nations, Ban Ki-moon, for World Autism Awareness Day in 2010, families suffer “a double burden”, comprising both “the daily challenges of
their disability” and “the negative attitudes of society, inadequate support for their needs and, in some cases, blatant discrimination” (Ki-moon, 2010)

In the early years of a child with ASD, parents experience an extremely stressful period while they desperately seek accurate diagnosis and treatment methods for their child. The difficulties they often have to deal with are multifaceted, beginning with their child’s challenging or even violent behaviours, social rejection, stigma and even bullying, as well as their own limited ability to work and the resultant financial difficulty. Gray’s (1994 & 2002) research on parents’ and siblings’ health and wellbeing and their social experiences in Australia found a significant level of emotional distress such as depression, anxiety and anger in parents, especially in mothers. About one third of parents receive psychological assistance. Regarding social experiences, parents reported a number of hardships such as “poor communication, inappropriate and embarrassing public behaviour, destruction in the home, violence and aggression, and obsessions with eating or toileting” (Gray, 1994). Children with ASD and their families are frequently alienated by parents of typically developing children at school and in the community. Particularly at the beginning or during the early years, parents are acutely sensitive to the reaction of outsiders and this leads to significant lowering of their self-esteem. A mother in Gray’s research said (2002, p 221):

And [when something happens] I just sort of stand there and glare at them and I just say, "Well, he’s autistic, what do you expect?" [And they say] "Oh, sorry, sorry, sorry." I’ve had to learn to be a little bit dominant too, you know, which I’m naturally not. But I’ve had to sort of pretend I am, sort of act it, yeah. And then people leave you alone.

Noting that the social support and research on ASD is still patchy and insufficient, and that numerous and diverse issues and hardships remain on personal and public levels, the recent decade saw considerable improvements in terms of social awareness, supporting social systems, research, knowledge sharing and practices, as a result of the massive collective effort of individuals (e.g., parents, educators, researchers, clinicians, welfare workers and policymakers). The importance of early and appropriate intervention is widely accepted to improve the lives of children with ASD. There are roughly two approaches which are applied in either one way, or combined: trying to correct or reduce the abnormalities with medication and training; or seeing children with ASD as they are, and giving the support they need to improve their lives.

Furthermore, a wide range of attempts from the practical to the artistic, have been, and will be, made to help individuals with ASD to fit in with society, often initiated by mothers Nicole Matthews (2008), for example, reports that the project, In the Picture (ITP) in the UK aims to make disability, including ASD, visible and socially included through the creation of picture books, facilitating interaction between individuals with and without ASD, and providing opportunities to evaluate and explore the genuine social inclusion of people with disabilities. New technologies are also utilised, for example, voices4u, an application for the iPhone and iPod Touch, which is a communication device for ASD and was developed in the US by Yumi Kubota, the Japanese mother of a son with ASD (Spectrum Visions, 2010). As Ryan and Runswick-Cole (2008) contend, mothers with disabled children inevitably go through a much broader range of experiences in terms of child-rearing than mothers of non-disabled children, whereby they become stronger and more able to address the situations. Lilley (forthcoming) urges to reposition ‘maternal expertise’ as ‘an important source of
personal and familial resilience", moving away from double binding parent-professional dichotomies. She also points out "mothers are frequently the authors and organisers of pedagogic efforts aimed at other mothers, politicians, professionals and the general community" (2009, p 2).

In this Introduction, we have looked at the general situation of ASD. However, each individual's everyday social experience and self-development are only shaped interactively in a specific socio-cultural, economic and political environment. The analytical consideration of the culture-specific aspects is therefore particularly important in discussion on the situation of ASD, as the core issue is centred around the difficulty experienced by individuals with ASD in social communication. In the rest of this paper, we will compare the social support provided in two countries, Australia and Japan, and identify the socio-cultural aspects that hinder the success of effective assistance for children with ASD and their families.

**Children with ASD and their Families in Australia**

In Australia, the rates of ASD have been rising significantly, as well as in many other countries, over the past decade, and two out of every three individuals diagnosed with an ASD are children under 15 years of age (Buckley, 2006). General awareness of ASD and effort towards early intervention have also been increasing, although many children and their families still suffer both from the disabilities and misunderstanding.

Parents who have their children diagnosed with an ASD early are advised to enrol their children in an early educational intervention program before the age of three to effectively improve symptoms and minimise challenging behaviours. A good intervention program should be intensive and individualised to meet the specific needs of each child. The Australian Government Department of Health and Ageing has therefore specified that, "a minimum of 20 hours a week over two or more years is essential for young children to make major gains" (Prior and Roberts, 2006), noting some of them may need more, up to 40 hours per week (O'Reilly and Smith, 2008). The early educational program is designed to work on the child's five essential skills: "to focus and pay attention; to imitate others; to understand and use language; to play appropriately with toys; to socially interact with others" (O'Reilly and Smith, 2008, p 42). The quality of the content is decided by careful individual attention paid to each child, hence, Australian experts encourage the child to be given an individualised education plan, specifically tailored to the child's and his/her family's needs. The family is involved in setting goals and plans, engages with their children in the assigned activities, and receives training in how best to communicate with their children (O'Reilly and Smith, 2008). The programs for children who will start schooling include a formal "transition to school" program or "integration" program. Autism Spectrum Australia (ASPECT) runs a variety of early intervention programs, such as Building Blocks, the Jigsaw Program, the Hanen Parent Training Program, the Picture Exchange Community System (PECS) and some intensive behavioural intervention programs, e.g., Applied Behaviour Analysis (see http://www.autismspectrum.org.au) Nearly every local council around Australia has a disability information officer or community care officer. Early Childhood Intervention Australia (http://www.ecia.org.au) is a national organisation which links to all states' early intervention services and promotes community support.

When it is time for children with ASD to start school, parents have to decide whether the children should enter special education settings or a mainstream school. As the majority of
children with ASD are in the high functioning/Asperger’s Syndrome end of the spectrum, they attend a mainstream school with some support. In some states in Australia, children can divide their time between attending a special setting and a mainstream school, but the number of special education schools is limited. Government autism specific schools can only be found in the state of Victoria. ASPECT Australia and Autism Queensland, the state autism associations, run six schools in NSW and three in Brisbane respectively. The NSW and ACT Education Departments also operate autism specific support classes in mainstream schools. Many government schools run inclusion support programs. There are 25 primary school learning support units, nine high school learning support units, 22 primary school learning support centres and 12 high school learning support centres in ACT (http://www.decs.act.gov.au), and there are over 60 ASD support classes across NSW. The NSW Department of Education and Training operates over 100 preschools that children with disabilities can attend (http://www.det.nsw.edu.au). The Department of Education, Training and the Arts has also implemented an Inclusive Education Policy (http://education.qld.gov.au/strategic/cppr/curriculum/cppr009/). These classes are smaller and teachers are generally trained in special education, together with a classroom assistant. Most state autism associations have a school outreach service, in which families find home schooling effective (see Home Education Association, http://www.hea.asn.au). State education departments can also provide information and instructions for home educators. There are also Giant Steps schools in Sydney, Tasmania and Woodbury, partially funded by government (http://www.giantsteps.net.au).

A range of services and benefits is also provided by the Government to assist families with children with ASD, as part of the larger scheme of supporting disabilities. Centrelink Australia provides financial support, through a Carer Allowance (child) to parents who are taking care of children with a disability at home. From 2007 onwards, an additional AUD 1,000 has been paid to these recipients. A health care card is also distributed to the child, which covers the cost of medicines and reduced entry to many theatres and theme parks (http://www.centrelink.gov.au). The Medicare Safety Net and Enhanced Primary Care (EPC), run by Medicare Australia, also subsidises medical costs (http://www.medicareaustralia.gov.au). Medical expenses on services such as speech therapy and occupational therapy can also be claimed as a tax rebate from the Australian Taxation Office (http://www.ato.gov.au). Regarding child care, families with a disabled child, including those with ASD, are eligible for the “In Home Care” program, run by the National In Home Child Care Association, if they find that the ordinary child care centres are unable to meet their needs (http://www.inhomechildcare.com.au). Moreover, there is a new source of funding, the “Help Children with Autism” package ($190 million), administered by the Department of Health and Ageing, the Department of Education, Employment and Workplace Relations and the Department of Families, Housing, Community Services and Indigenous Affairs, which over 6,300 children have accessed since October 2008 (Shorten, 2010, http://www.health.gov.au/autism). The package aims to provide earlier diagnosis, and assist families to get access to early intervention programs as well as other services.

In terms of mental and psychological support for the families, there is a range of services. There are approximately 90 Commonwealth Carer Respite Centres and Resources Centres across Australia, all administering a program named the National Respite for Carers Program, which aims to provide support for carers of people with disabilities. The National Carer Counselling Program run by the Resource Centre provides a free counselling service (ht-
The Home and Community Care Program, which is a joint Australian state and territory program, provides community care services for young people with disabilities and their carers. Over 3,000 organisations across Australia administer such programs. Parents who would like to meet people in a similar situation and find out about information available in community support can access MyTime groups. These are local playgroups that provide support for families caring for young children under school age with disabilities. Each group has a play helper who engages the children in activities, while parents can socialise and share ideas with others (http://www.mytime.net.au). Another service provider, Early Days, offers free workshops for parents and carers of children aged six years and under who have an ASD. Early Days is part of the Australian Government's Helping Children with Autism package. The workshop includes information and discussion sessions that help carers to apply practical ideas and strategies regarding their own situations.

Moreover, some state autism associations run sibling support programs, such as Siblings Australia (http://www.siblingsaustralia.org.au).

In terms of cultural specific issues, it should be noted that Australia is an English speaking country where the western approach of ASD is practiced, yet it is the world's most multicultural society. A great number of people who live in Australia are originally from countries all around the world, and obviously these people are different culturally and linguistically. Although the public's awareness of ASD has greatly increased and social inclusion has always been highly advocated within the society, cultural diversity can be a hindrance to the practices of interventions used to support the communication development of children with ASD (Dyches, Wilder, Sudweeks, Obiakor, & Algozzine, 2004; Trembath, Balandin & Rossi, 2005).

For instance, some families may not seek community support or services, not because of their socioeconomic status, but because of their lack of familiarity with the major culture (Dyches, et al., 2004). In some cultures, such as Asian and Hispanic, the idea of family cohesion may prohibit them from seeking help from outside the family. Traditional thinking, such as Confucianism, and religious thinking, such as Catholicism, which advocate that ideal mothers be self-sacrificing and dedicated to their children and families, may lead some mothers to feel obliged to take up all the responsibilities for raising their children (Dyches, et al., 2004).

Regarding many early intervention programs, therapists often request parents to play an active role in engaging their children in activities and also in practising these activities at home. However, some parents may be less willing to be involved in teaching their children, rather expecting the professionals to cover all educational training, due to cultural differences in the practices of child raising (Hwa-Froelich & Vigil, 2004). As a result, these parents may find it hard to adapt to the programs and therapists may also experience difficulties in collaborating with the parents.

The majority of services and support provided in Australia are predominantly targeted at families from an English speaking background or families who have a considerable level of English language skill. Incompetency in English may prevent families from getting in touch with their local community services because of their anxiety about failing to be reasonably understood by the service providers. As Dyches, et al. (2004, p.221) have stated, "multicultural students have more difficulty with the academic and behavioural customs of the school culture than students from the dominant culture". Racial differences and cultural diversity
may worsen communication problems and affect the services available for students with ASD. Therapists and practitioners may need to consider other methods or approaches to meet the needs of different cultural groups (Trembath, et al, 2005). In the context of Australia, a multicultural nation, a lot of work and effort are still required in order to meet the individual needs of different families.

Children with ASD and their Families in Japan

In contrast to multicultural and multi-ethnic Australia, Japanese society is highly homogeneous, contextualized and often hierarchical. Many difficulties involving ASD lie in the socioeconomic and political context. In addition, there has been a long-term misconception of autism, derived from the impression of the term 'Jibeishō' (lit. an insular syndrome) used for autism, as a mental problem, rather than neurobiological disorder. This has caused unnecessary and inappropriate adversity for the individuals with ASD and their families, and has considerably delayed the development of social support systems.

Probably because of recent promotion of social awareness of ASD through various media, the mental health literacy of ASD in the general population in Japan appears to be at an acceptable level, although there are disparities due to sex and generation, showing that females showed more accurate knowledge (Koyama, et al. 2008). Having knowledge is an essential first step in improving the lives of individuals with ASD; however, there are specific cultural issues that may prevent them from being provided with effective and inclusive social support. Note that many issues are common with other disabilities and there are insufficient specialized services available for ASD.

In Japan, it is common to deliver information via printed matter and there are many introductory (often manual-like) books (e.g., Beppu 2009; Goto and Kaibara 1995; Sato 2004; Takanura & Tokyo Jibeishō kyoukai 2009; Tanaka 2006) and some journals (e.g., Jibeishō kyoiku no jissen kenkyû) which emphasize the importance of individual care with careful observation, practicality, sensitivity and thoughtfulness. ASD-related research and practices in Japan have relied heavily on Western research outcomes, as exemplified by the journal, Jibeishō to hattatsu shōgai kenkyû no shimpô (Takagi Ryûrô, Michael Rutter and Eric Schopler eds. 1997-2006), which was established to introduce Western research publications.

The Japanese society consists of a number of small groups that the political scientist Maruyama Masao figuratively depicts as 'takotsubo-gata' (a round ceramic pot for catching an octopus), as they exist in isolation, with limited security and freedom inside. Each group demands from its members normative 'role-playing'; according to what is deemed appropriate in each situation, often promoting competition, inner surveillance and disrespect of an individual's integrity. The true sense of individualism has never prevailed in the society under the Japanese style patriarchal system, in which a household, not an individual, is regarded as the basic social unit. The double standard of (honne=true voice and taemae=facade) is often employed as a pragmatic method for people to conform to requirements without expressing the 'inner conflict' caused by the 'role-playing'. Such adaptability is regarded as an essential qualification for being an 'adult', maintaining a 'harmonious society'.

In such circumstances, people with any disabilities can be regarded as disruptive and the care of them becomes a 'private matter' of the household, i.e., a family responsibility. If families are unable to take care of them, institutionalisation is the main alternative solution. According to Teramoto (2008), approximately 130,000 individuals with disabilities are in-
stitutionalised. This situation makes their presence and struggle invisible in society, as epitomised by the considerably small number of wheelchair users still today, due to the insufficiency of tangible and intangible accessibilities. Therefore, the hopelessness of ageing parents is intense. Even compared with physical disabilities, the laws, legislation, welfare and education systems to support children with developmental disabilities including ASD and their families have been delayed significantly. It was common until very recently that due to their ignorance, people, including family members, frequently and harshly accused mothers of children with ASD of failure in child-rearing. In addition, prejudiced attitudes in communities often alienate individuals with ASD and their families, as exemplified by the case of a young man with severe ASD who was supported by a welfare group and tried to live independently, but the worried neighbours used their knowledge of ASD and provoked his autistic reactions in order to evict him (Iwahashi 2008). Consequently, the care of those children has fallen heavily to specific individuals (e.g., parents, teachers, doctors, psychologists and other helpers), parental support groups, and associations such as the Autism Society Japan, 1 schools (often private) 2 and welfare institutions (see for example, http://zenjisyakyo.com/shisetu.html).

Furthermore, the Japanese education system, similar to many other socio-cultural and legal systems, is age-based and collectivistic. It has been, and still is, in many areas, inflexible, with strong pressure for conformity and a reluctance to consider the specific needs of individuals, to suit varied levels of intellect and maturity, and physical or psychological conditions. As a result, until the end of junior high school, outstanding students and students who lag behind often sit in the same classroom. This superficial egalitarianism provides little or no recognition of individual differences, thereby requiring all students to persist with their studies under possibly ineffective educational strategies, rather than searching for alternative ways of learning. Such circumstances are especially incapable of accommodating individuals with ASD without indicting, and alienating, them and their family as strange, selfish, shameful and anti-social.

Moreover, Japanese early education tends to attach importance to students’ social skills, rather than their academic skills (Haynes, 2000, referred to in Hayashi, Karasawa and Tobin, 2009). Emotions, especially empathy, are employed to educate social harmony from childhood. Hayashi, Karasawa and Tobin (2009), for example, report that Japanese preschool pedagogy is built on Doi Takeo’s concept omae (expressions of dependency needs) and emphasise empathy to loneliness and other expressions of need as a means of social connection. Failure to empathetically understand others’ feelings in a specific context to behave appropriately is therefore criticized as destructive and selfish, as exemplified by a teasing expression, KY, which stands for ‘Kuki ga yomenai’ (people who cannot read the atmosphere). These cultural issues exacerbate the hardship imposed on people with disabilities, especially those with ASD, who are unable to decode facial expressions, atmosphere and the situational context. It also puts an extra burden on their parents to obtain sincere communication with other people, especially when they want to send their children to “ordinary” schools. Furthermore, intolerance of differences is often manifested more ruthlessly in relation to someone

1 http://ajdknet.jp/index.html The Autism Society Japan was established by parents of children with ASD in 1968 and now has branch offices in all prefectures in Japan, providing a wide range of services and promoting social awareness of ASD.

2 For example, Kitahara Kiyo’s Mushashino Higashi Gakuen (since 1964) and its Boston Higashi School (since 1987) promote inclusive education and the International Program for Individuals with Autism <http://www.bostonhigashi.org/>
who is slightly different (with mild disabilities), than in relation to someone who is totally
different (e.g., with severe disabilities). This can prevent the social inclusion of children
with less severe ASD due to their behavioural issues.

In such a society, popular mass media, such as manga, anime, TV dramas and movies,
often play an effective educational role, by dramatising individual challenges and engaging
emotionally with audiences. For example, Tobe Keiko’s manga, *Hikari to tomo ni (With the
Light, 2000-2010)*, skilfully depicts the wide-ranging hardships, Hikari (a child with severe
ASD) and his parents face, and how they overcome these hardships through the involvement
of people around them. It is a story of the development of the social interactions of a group
of people centring on Hikari. The first part of the story was also created as a TV drama with
the same title and broadcast in 2004, promoting social awareness of (severe) ASD. Japanese
culture attaches importance to empathy and such use of media effectively promotes social
awareness. Nevertheless, as Stibbe (2004) argues, the representation of these narratives as
touching personal stories may reinforce traditional social and medical frameworks, rather
than contributing to fundamental social improvement.

It is only since the beginning of this century that the Japanese education system for children
with special needs has finally gone through considerable changes at a governmental level,
in order to implement inclusive and supportive education in a cohesive society, by providing
support to meet individual needs. In April 2005, legislation of the Support Law for People
with Developmental Disorders was established, aiming at “supporting people with develop-
mental disorders throughout their lives with regard to their self-sufficiency and social partic-
ipation, hence contributing to the promotion of welfare” (The Ministry of Health, Labour
and Welfare, 2007-8; for a summary, see Tokunaga, 2005) This was a critical change and
since then, with governmental support, a number of initiatives have begun, nationally and
regionally. For example, the National Institute of Special Needs Education (NISE) began to
supply information for Special Needs Education. In 2007, reform of special education
commenced, moving towards being more inclusive. Cooperation has been improved amongst
key stakeholders, such as private and grassroots organisations, municipal, prefectural and
national governments, the Ministry of Health, Labour and Welfare and the Ministry of
Education, Culture, Sports, Science and Technology. This cooperation is further reinforced
through the interlinking of their websites.

There are two systems for children with special needs in ordinary elementary and lower
secondary schools: small “classes for special needs education” (up to 8 students); and “special
needs services in resource rooms” for children who are enrolled in regular classrooms
(Fujimoto, 2009). Such classes began to be used for emotionally disturbed children in 1969,
and in 2009 there were 13,852 special needs classes for a total of 43,702 students with dev-
velopmental disorders and/or emotional disturbance. Special needs services in resource
rooms were initially available in elementary and lower secondary schools in 1994, and only
in 2005 were they officially made available for children with ASD, learning difficulties and
attention-deficit hyperactivity. The situation poses a question whether the special needs of
children with ASD are sufficiently and appropriately evaluated and catered for, when they
are often categorised and handled together with emotionally and/or intellectually disturbed
children, even in special schools for children with disabilities.

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1 The website also includes information and a promotional video regarding Autism awareness (http://nettv.gov-
online.go.jp/pg/peg3288.html)
A number of individual attempts have been made to utilise the still limited resources to improve the lives of children with ASD (and other developmental disorders), relying heavily on the efforts of individuals. Although the value of the effort of individuals is acknowledged, such a heavy reliance on the goodwill, devotion and capacity of individuals is precarious for the children, as such support may not always be available, especially where these individuals are often unaided and stressed. This situation is well depicted by Tobe’s manga, when Hikari and his family experience severe shock and disastrous consequences when his excellent teacher is replaced by an incapable, ignorant and unwilling teacher. It is evident that one pressing issue lies in the insufficient cooperation among individuals, schools and communities (Yokoo and Matsumura, 2008). It is also interesting that teachers tend to perceive the main cause of learning disabilities not as in an individual student’s characteristics and abilities, but as inadequate support provided by parents, teachers and society, which is different from Australian educational practitioners (Kataoka, van Kraayenoord and Elkins, 2004).

The issues with ASD epitomise the situation of all disabilities in Japan. As in many countries, including Australia, Japanese approaches to ASD are in the Western framework, based on respect for the individual and human rights. The actual practice is, however, appropriated to the Japanese socio-cultural context, in which even requests for the necessary support for individuals with ASD and any other disabilities are expected to be made as humble pleas, rather than as a demand for human rights. More so than their Australian counterparts, Japanese mothers with autistic children may have to bear social pressure, which lowers their self-esteem and confidence. Instead, the thoughts, experiences and energies of the families, especially of the mothers, of children with ASD should be valued and utilised so that the genuine and effective social inclusion of individuals with ASD can be implemented throughout their lives. Furthermore, although still very limited, some individuals with ASD have started to express their voices publicly, for example, Komichi (2009) uses manga-style illustrations together with her reflection of herself and her interactions with others from her perspective, helping readers to understand the core issues of ASD. What is needed is to overcome the suffocating collectivism in Japan, and the development of broad, holistic and well-connected supporting structures from the government level to the individual level, including individuals with ASD, with practicality as well as sensitivity, compassion and respect for individuals, in order to ensure all participants (e.g., the children with ASD, their parents, the teachers, other parents, other children and the general public), as equals, are included firmly within the community.

Conclusion

This paper has first looked at the core issues of individuals with ASD and their families, followed by discussion of the Australian and Japanese situations to examine the varied socio-cultural conditions and possible cultural hindrances to successful implementation of support (such as early intervention programs). In general, Australia’s approach seems more practical and widely accessible with better connectedness between individuals and supporting systems. Moreover, both in Australia and many other western countries, the influence and power of mothers is becoming strong. In Japan, the support system for people with ASD is still precarious, as it relies strongly on the goodwill and devotion of individuals, due to the insufficient provision of easily accessible social support structures, as well as Japanese socio-cultural
restrictions that regard support not as a ‘right’ but as a ‘gift’ or ‘mercy’. This situation compels individuals with ASD and their families to position themselves as passive recipients of social support, despite their invaluable knowledge and experiences that could contribute to the improvement of the situation. It is extremely difficult for a mother of children with ASD to obtain professional qualifications as an educator, doctor or researcher, after having had the children.

For many decades, individuals with ASD and their families have been struggling with relentless, multiple hardships from ASD itself as well as from social ignorance and negligence. Many grassroots activities have been developed from their hardships and challenges. In this decade, at last, the magnitude and complexity of ASD has been publicly recognised, as exemplified by the establishment of World Autism Awareness Day. Consequently, the level of social awareness of ASD has risen and research and social support have improved considerably. Governments and societies in many countries have gradually implemented a variety of intervention programs and support for individuals with ASD and their families, often integrating the previously developed grassroots activities, networks and facilities. Information technologies are also offering great support, by connecting isolated individuals in need, sharing knowledge and help, as well as producing effective communication devices. Nevertheless, the genuine social inclusion of individuals with ASD is still far from being realized. It requires something beyond ‘general awareness’. All participants, that is, the individuals with ASD and others, should concurrently be involved on very personal and collective levels. The keys to success are extreme patience, love and compassionate imagination to genuinely understand the world of people with ASD and find some common ‘language’ to communicate. Such efforts inevitably challenge who we are and how we physically and emotionally interact, which also includes how we are bound by specific socio-cultural contexts. To overcome complex disability, it is therefore important to holistically develop practical, comprehensive and cohesive social support at all levels from individuals to community and government, with respect for an individual’s human rights, regardless of the condition of the person.

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About the Authors

Poon Lung Ku
Macquarie University, Australia

Dr. Mio Bryce
Senior Lecturer and Head of Japanese Studies in Dept. of International Studies at Macquarie University, teaching Japanese language, literature and manga related units. PhD in Japanese classical literature, The Tale of Genji, from the University of Sydney. Mio is particularly interested in historical, socio-cultural and psychological issues depicted in fiction. She is currently involved in interdisciplinary research into youth cultures, with particular focus on manga and anime, in conjunction with the English Department at Macquarie University.