



# Japanese culture and the philosophy of self-advocacy: the importance of interdependence in community living

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(Citation)

British Journal of Learning Disabilities, 34(3):151-156

(Issue Date)

2006-09

(Resource Type)

journal article

(Version)

Version of Record

(Rights)

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(URL)

<https://hdl.handle.net/20.500.14094/90000481>



## **Japanese culture and the philosophy of self-advocacy : the importance of interdependence in community living**

### **Introduction**

This article explores the relationship between the philosophy underpinning self-advocacy and Japanese culture. It considers the variety of self-advocacy groups that have grown in Japan, and the context in which they have emerged. Elements of Japanese culture present a specific set of challenges for the values and ideas driving the global self-advocacy movement. This paper examines the ways in which these ideas may need to be negotiated in order to support greater community living for people with learning difficulties.

In Japan, the age of de-institutionalization is gradually arriving, but progress has been quite slow. There are currently many small or medium-sized institutions, and a number of large institutions (between 300-500 residents), continue to exist across the country. Institutional closure has scarcely progressed and available statistics indicate that both the number of institutions and the number of residents actually increased in 2002.<sup>1</sup> One of the few exceptions to this situation is the Funagata Colony, which has announced a closure plan and is now trying to develop a system to assist the community living of its 370 residents by 2010.

The Ministry of Health, Labour and Welfare published the New Plan for People with Disabilities in 2002, declaring that no new institutions would be built. People with learning difficulties presented their comments at the Cabinet Office as this plan was being drawn up. Their comments begin: 'We want to be listened to. People with learning difficulties have to be members of the committee when discussing a plan for people with disabilities.' Moves towards deinstitutionalization have been accompanied by changes to the social welfare system for people with difficulties. Services had previously been granted by government to individuals, but following this welfare reform (2003), individuals are now able to choose their own services which are then paid for by the government. The intention was that the system should change to a customer-centred one, based on the self-determination of people with difficulties (Ministry of Health and Welfare 2004).

### **Japanese society and community living for people with learning difficulties**

The system of 'traditional native organizations' was established during the Edo era – from the 17th century to the mid-19th century. These organizations were established as agencies of rule and control at the local level and facilitators of mutual help. Even during the modernization of Japanese society these organizations have retained a powerful role. Whilst this governing system has arguably enabled paternalistic attitudes and gender inequalities to persist for a substantial period, it has also been a pillar of prosperity for local communities. Although household and village networks

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<sup>1</sup> 69,986 people with learning difficulties lived in institutions in 1990 and 104,518 in 2002 (Ministry of Health and Welfare, 2002)

have declined since World War Two, Shiobara (1996) has argued that Japanese society has continued to benefit from the vitality created by the existence of traditional native organizations.

Individuals in Japan do not usually advocate for change within native community organizations as they are supposed to live their community lives in a structure of mutual dependence (Ben-Ari 1991). Therefore, observing convention without self-assertion is the means to acquire support from the community. Such a traditional Japanese climate has been recognized as 'pre-modern' or 'conservative', and has been a target for change (Okuda 1971). In actual fact, the community organizations have tended to decline – particularly in urban areas – as population movement has become more intense. Such established networks have been eroded by a decreasing population, accompanied by increasing urbanization and individualization, as a result of the rapid economic growth since the end of 1950s (Economic Planning Agency 1969; Ministry of Health and Welfare 1997). However, as conventional community organizations are often firmly entrenched in local governance systems, they are unlikely to be dismantled in the near future, and today many of these organizations still remain in urban and rural areas (Iwasaki et al. (eds) 1989).

The role of traditional native organizations in supporting and advancing community living for people with difficulties should not be overlooked. Creating harmonious relationships with these organizations is a sound strategy to pursue when seeking to promote community living. One example of the importance of the organization in the community is participation in the traditional village festival. By identifying themselves as members of the community through active participation in the village festival such events act to confirm an individual's inclusion in their local community. This highlights the potential significance of traditional organizations in the development of community living for people with learning difficulties in Japan. The relationship between this local organizational system and self-advocacy is considered later in this paper.

### **The role of parent groups in campaigning for change**

Parents, especially mothers, have taken up important roles in the development of community living for people with learning difficulties in Japan. There are numerous cases of parents challenging the community to change the way it provides for people with learning difficulties, which stem from a concern about their children's quality of life in the community after their death (Tsuda 2000). However, the survival of such campaigns is reliant upon ongoing parental commitment – and this is not always easy when parents are sometimes faced with a lack of support from the wider community in which they live. Some of these parent groups have tried to establish sufficient funding with which to start supplying formal services – such as home help services, day care services, guide help services<sup>2</sup> and group homes – as a means to support community care. However, the financing of these projects is often too precarious to sustain a high level of community living for people with learning difficulties.

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<sup>2</sup> *This refers to helpers who take people with learning difficulties out, wherever s/he wants to go. This service is considered as essential for community living for people with learning difficulties.*

As well as campaigning for the provision of local community services, the parents of people with learning difficulties have also been involved in the development of policies and services at the national level in Japan. Inclusion Japan is the most notable and wide-spread example of a parents' organization in Japan lobbying for change. Inclusion Japan was established in 1952 by three mothers of children with learning difficulties, all of whom lived in the same local area. It has gone on to become a national association of parents, and has taken up a number of important roles. For example, Inclusion Japan contributed to the establishment of the social welfare policy for people with learning difficulties in Japan, in particular the Law for the Welfare of Mentally Retarded Persons (1960). This was the first significant piece of legislation for people with learning difficulties in Japan, and was enacted mainly by virtue of Inclusion Japan's campaigning. The organization also became involved in service provision, and established institutions to house people with learning difficulties after their parents' death. In the current era of de-institutionalization, Inclusion Japan has changed its policy, and now campaigns for community living for all. A significant part of its remit today is supporting the Japanese self-advocacy movement (Inclusion Japan 1991). For example, Inclusion Japan has organized seminars and workshops for advisors of self-advocacy groups from 1997 to 2001. The organization has also compiled textbooks for self-advocates on the subjects of social welfare services, the law, sex and marriage, health promotion and cooking.

### **The growth of self-advocacy in Japan: different settings; different purposes**

The first officially acknowledged self-advocacy group of people with learning difficulties in Japan – 'Sakurakai' – was established in 1990, and since then the self-advocacy movement has spread throughout the country. Self-advocacy in Japan now includes People First organizations, as well as a variety of recreational and educational groups. Whilst not all of these groups outwardly describe their activities as 'self-advocacy', much of their practice resembles strong elements of the self-advocacy movement. One such group was established as long ago as 1969. Inclusion Japan reported in 2004 that there were 142 self-advocacy groups in Japan, although this list includes only the groups which Inclusion Japan has relations with (Inclusion Japan 2004). Most self-advocacy groups in Japan identify themselves as 'Honin no Kai' which means 'a group of our own'. Self-advocacy groups in Japan vary with regards to the activities they are involved in. As will be described below, some organizations have engaged heavily in political action and have made significant alliances with parent groups. Other self-advocacy groups concentrate their attention on social and educational activities.

#### *Campaigns for change: self-advocacy and alliances with parents*

Sakurakai, which was established in 1990, is formally recognized as the first self-advocacy group in Japan, and is an outstanding example of self-advocacy in action. The members participated in an International People First Conference, and were inspired by the global movement of self-advocacy to organize the first self-advocacy group in Japan (Tateiwa & Teramoto 1997).

Inclusion Japan has attached much importance to supporting the self-advocacy movement since 1990 when Sakurakai was established. Inclusion Japan has

organized seminars for self-advocates and advisors and tried to support fledgling self-advocacy groups by sending leaders of advanced self-advocacy groups to speak with them. As we have heard, it has also edited texts for self-advocates and advisors, and newspapers for self-advocates. There is a self-advocates' meeting at the national conference which is held by Inclusion Japan every year. Self-advocates state their opinions on various themes, and an agenda based on the statements is resolved at the meeting. The topics of the agenda include participation in the political process; reduced fares on public transport to facilitate social inclusion; simple ID cards; service information; and building a safe community where people with learning difficulties can live after their parents' death. It is worth noting that, according to a research survey in 1997 (Mitsumasu & Honma 1997), one third of self-advocacy groups in Japan were advised by parents or a parents' organization. Further research suggests that the self-advocacy advisors who are parents of self-advocates tend to think that self-advocacy is a training opportunity and the groups which are advised by these advisors tend not to be particularly self-advocate-centred (Tsuda & Smith 2004). The current alliances with parents and parent-led organizations might therefore have significant implications for the development of self-advocacy in Japan.

Japan also has a number of People First self-advocacy groups, and a national People First conference has been held in Japan every year since 1994. 'People First Japan' was formally established in 2004, and is to date, the only national self-advocacy organization in Japan. People First groups have drawn inspiration from the actions of the Japanese disabled people's movement (Hayashi & Okuhira 2001). The following statement from People First Japan provides an example of the resolutions made at its 2004 annual conference:

*parents, government, schools and institutions have decided without us what concerns us. We have felt sick when we are sent to places that we do not like, such as special schools or special classes. We have also been sent to institutions if we have trouble living in the community. But we have rights to live as human beings just as other people. Nothing about us without us. We fight against any discrimination with the encouragement of our peers.*

There are some significant examples of political actions undertaken by People First groups. For example, Hyogo People First has appealed for years to local government to recognize guide help services as formal services. As a result, the local government of Kobe city decided to pay for guide help services in 2003. The establishment of People First organizations and their campaign-orientated agendas, links the growth of self-advocacy to the wider, global self-advocacy movement.

### *Self-advocacy and recreation*

Whilst the growth of People First and 'Honnin no Kai' groups demonstrates the political wing of self-advocacy in Japan, survey research on self-advocacy groups has reported that recreational programmes are the main activities of many groups (Mitsumasu & Honma 1997). I also found evidence of this in a qualitative research project that I undertook (Tsuda 2003). For example, 'Friend', a self-advocacy group in which I am an advisor, has engaged mainly in planning and executing recreational programs. A couple of suppositions might help to explain why recreational activities in self-advocacy are afforded such high priority in Japan. First, if recreational

programmes are planned well, it is possible for them to involve community members. Secondly, because self-advocates enjoy recreational activities it raises their motivation, and this in turn makes it relatively easy for people to experience accomplishment and a sense of self-esteem. A self-advocate who leads an outstanding self-advocacy group in Japan demonstrated this point when he said in a seminar:

*Coordinator: Tell us your plan or dream of your group.*

*Self-advocate: I want to accomplish well the group activities, like I said before.*

*Coordinator: Tell us exactly what the group activities are.*

*Self-advocate: Balls or karaoke which everybody loves. The reason why they are good is that they can attract members. We asked members what they wanted to do in the group and they answered that they wanted to play balls and karaoke.* (Inclusion Japan 1997)

When members of the 'Friend' self-advocacy group felt limited by the recreational programmes, they started editing and publishing a newspaper in order to develop another channel through which to communicate with the wider community. This newspaper is published twice a year, and has attracted people's attention through its unusual style. For example, articles are written with the spontaneous appearance of professional sports players' names in the middle of articles, or by the inclusion of impressive – but unrelated – illustrations in the text. The newspaper is an interesting example of self-advocates producing and conveying knowledge and meaning to one another.

### *Self-advocacy and education*

There are also several self-advocacy groups which have progressed independently of the groups discussed above, and some have helped to pave the way for later developments in self-advocacy. There is a deep-rooted view in Japan that people with learning difficulties should have longer-term educational opportunities, because it usually takes them longer to learn (Oishi 1975). This view has led to a movement which has established educational opportunities for adults with learning difficulties. Classes for Youths with Disabilities are an example of such opportunities, which began in 1956 in Tokyo. An aim of some of these classes is to foster learning that is created by self-advocates rather than conferred by educators and advisors. In some ways they resemble many features of typical self-advocacy groups, and at times excel in terms of their people-centred approach (Kobayashi 1996). The Tsukushi Circle in Nanao city (a rural area of Ishikawa prefecture) was established 35 years ago and has been developed as an independent group in which self-advocates' autonomy is sincerely respected (Tsuda 2003). The Tsukushi Circle was originally established in 1969 by teachers and parents as a special class aftercare service for children with learning difficulties. Then members of a community organization of youths (Seinendan) voluntarily got involved in the circle and they finally became practical advisors when teachers and parents withdrew from the group in 1975. Some of the prominent current members – both self-advocates and advisors – have been members since the group's establishment. Most advisors are not professional social workers but salaried workers or businessmen. They feel that they have developed mutual peer relationships with the self-advocates, rather than one-way relationships that are mediated by support action. The group started to vote for officers about 20 years ago in the natural course of events. They have officers' meetings every month to discuss

an agenda and ways to proceed with the meeting. Self-advocates take charge of most of the tasks involved in administrating the group meeting, and determine how advisors are used.

The Tsukushi Circle is unique because whilst it appears to have developed activities in keeping with the philosophy of the global self-advocacy movement, unlike People First Japan, this group has not made direct international links. The Tsukushi Circle is also committed to the philosophy underpinning the traditional rural community organizations in which members spontaneously help one other. A comment that an advisor mentioned was quite impressive. He said 'We clean up wherever the group uses for activities. Members do not hesitate to polish even toilet stools barehanded. People in the community gradually have recognized the members because of these actions' (Tsuda 2003). The way in which the Tsukushi Circle has managed to develop links with their local community might be an interesting model for other self-advocacy groups to consider. It also serves to highlight an operational model that could be considered a particularly 'Japanese' style of self-advocacy.

### **Discussion: questions and issues regarding the growth of self-advocacy in Japan**

The philosophy of the international self-advocacy movement originally attached an importance to action, based on the self-determination of people with learning difficulties to improve their own social status or their quality of lives, and to transform their relationships with others from dependence to independence (Pennell 2001). It is natural to think of independence and self-determination as important notions for action, as disadvantage through dependency has been viewed as a serious problem for people with learning difficulties. It is, nevertheless, debatable that a philosophy based on independence and self-determination is truly acceptable in Japanese culture. Independence in the context of the disability movement is a notion that represents personal action, for instance living away from parents or institutions, acquiring skills not to depend others, and asking people for help. Interdependence, on the other hand, is a notion that represents relationship. It is worth acknowledging that the notion of independence has also been critiqued within the Western Disability movement. Reindal (1999) argues that the dependence-independence dichotomy has arisen from individual models of disability and the notion of interdependence is adequate for social models of disability. In terms of self-advocacy, it could be argued that the cultural context has implications regarding whether the movement needs to attribute greater strategic importance to either notions of personal action or the development of relationships (Louie 2000).

It is difficult to speak of an 'essential' Japanese culture, as Japan has been heavily influenced by America and the West over the past few decades. Nevertheless, a number of commentaries have explored the differences between Japanese and Western cultures. It is often said that strong norms still remain alive in Japanese society which are represented by proverbs such as 'The nail that sticks out gets banged down' or 'When in Rome, do as the Romans do' (Nakamura 1988; Nakane 1970). It means that offensive manners tend to be avoided and smooth relationships with others tend to be respected in Japanese culture. Notions such as self-determination and independence are sometimes thought of as the source of offensive relations with others. For example, Hayao Kawai, a Japanese Jungian psychologist, suggests that the

position of self is different in Japan from western countries where psychology was originally established. According to Kawai, establishment of self has been an issue in the modernization of Japan, but it is still said that Japanese people's self always exists only in mutual relation with others and is not established as individual (Kawai 1995). Aside from the psychological critiques of 'independence' in Japan, a number of social factors point to a culture in which interdependence is also deeply embedded. This can be seen in the number of people in their twenties who continue to live at home with their parents. It is an ongoing Japanese tradition that families accept this situation, and it is quite commonplace in Japan that parents and their children's family live together. For example, more than 26% of all couples in Japan live with their parents (National Institute of Population and Social Security Research 2001). There is a well-known term 'parasite single' (Yamada 1999), which refers to people who live with their parents until their late twenties or early thirties in order to enjoy a carefree and comfortable life. The Japanese form of independence from parents is probably different from the Western form, and an interesting example of where the cultures diverge.

Interdependence is therefore a deeply entrenched notion in Japanese culture, and has particular relevance for people with learning difficulties as community living struggles to become established. In many instances, even self-advocacy groups can only exist through the excessive endeavours of the parents of self-advocates. As people with learning difficulties are at risk of being perceived as a burden, concrete relationships have to be established in the community. Independence or self-determination – keywords of the self-advocacy movement – do not emphasize the value of making and deepening mutual relationships. In fact, it could be argued that they seem opposed to the creation of these mutual relationships which provide the basis of community living (French, 1993).

## **Conclusion**

An appraisal of Japanese culture leads us to some complex questions regarding the nature, and future direction of self-advocacy in Japan. This paper has raised three areas that appear to merit further consideration at this stage in the movement's development:

- A dimension of the self-advocacy movement in Japan is a process of constructing new collaborative relationships between parents and people with learning difficulties in order to establish the basis of community living. Does the nature of these alliances and their implications for the empowerment of people with learning difficulties need further examination?
- Concepts of independence and self-determination seem to have been accepted by leaders of the self-advocacy movement in Japan and are currently being used to educate parents as well as people with learning difficulties. As argued above, these concepts may have only limited application in Japanese society. How can the self-advocacy movement in Japan engage with the concept of 'interdependence' and the need for associated skill development?



- An integral aim of self-advocacy groups is to make people with learning difficulties recognized and included in community networks and organizations. How to develop relationships with community organizations, and where necessary to change them, are therefore key issues for self-advocacy groups who seek to establish a basis for community living. A self-advocacy movement embedded in Japanese society could work towards the positive establishment of relationships based upon interdependence rather than independence (Reindal 1999; Tsuda & Smith 2004).

As de-institutionalisation in Japan progresses, a strong self-advocacy movement is essential to facilitate and support the successful community living of people with learning difficulties. This article highlights the challenges of this task and suggests a possible way forward through the adoption of the 'interdependence' concept.

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