

## **THE HISTORY OF SELF-ADVOCACY FOR PEOPLE WITH LEARNING DIFFICULTIES: INTERNATIONAL COMPARISONS**

### **Report on the conference held on 6-7 May 2004, at the Open University, Milton Keynes**

On 6 and 7 May 2004, the Social History of Learning Disability Group (School of Health and Social Welfare, the Open University) hosted an international seminar on the history of self-advocacy for people with learning disabilities, generously funded by the Wellcome Trust. The aim of the seminar was to give self-advocates, supporters and academics the opportunity to discuss their memories and knowledge of self-advocacy in their respective countries, to help build a bigger picture of how self-advocacy has developed historically within the international context. To date, much of the literature on the history of self-advocacy has tended to focus on local and national perspectives, and it was hoped that the seminar would provide a forum in which to move beyond these boundaries and enrich our understanding of the meaning of self-advocacy, and how we might approach both its history and its present form. The Social History of Learning Disability Group also anticipated that the seminar would be an occasion for those users, supporters and academics working in the field to forge new links, as well as strengthening old ones, in order to stimulate more comparative international work.

A number of themes relating to self-advocacy emerged from the conference. The international dimension revealed as many similarities as it did differences regarding not only the history of self-advocacy in different countries, but also in the various stories of its subsequent development to the present day. Some of the most pertinent issues raised at the seminar have been organised here under a few broad themes. Although these headings are to an extent arbitrary (as many issues can be found to overlap different themes), it seemed useful to try to present some of the 'big ideas' that arose during the papers - and in the discussion that followed - in a systematic way. This will hopefully make it easier for people to engage with some of the exciting findings about self-advocacy that surfaced at this trans-national forum, as well as encouraging further research to follow them up where possible.

Although extensive literature exists relating to the question ‘what is self-advocacy?’, the seminar highlighted the wide range of meanings attributed to the term in different countries. Speakers from across Europe and Japan discussed the concept of ‘self-advocacy’ on a variety of levels, spanning personal (and often isolated) incidences of ‘speaking up’, to the creation of formal self-advocacy groups, and in some cases, national organisations. The papers illustrated that in trying to establish an epistemological premise from which to explore both empirical and theoretical approaches to self-advocacy, we need to take account of the multiple meanings ascribed to the term, and how these meanings have been shaped by different histories.

The following sections will explore some of the more specific ways in which the history of self-advocacy has developed in parallel and divergent ways in the international context. The first section will address the origins of user-groups in different countries and consider whether we are able to see any patterns emerging across both local and national movements. In looking at this more ‘formal’ aspect of self-advocacy, it will also draw upon other issues raised at the seminar which include groups’ funding strategies, expansion, objectives and activities.

The second section will consider the personal expression of self-advocacy, told so evocatively at the conference through a number of life-histories. It will compare the actions taken by people with the label of ‘learning disability’ which show them exercising self-advocacy in an individualised way, in a variety of settings, across many decades. It will explore how life-histories are being used internationally to reveal the voices of people who have traditionally been silenced, and contemplate the point at which personal reflections about ‘speaking up’ may develop into collective action.

The third section will examine relationships and networks within the history of self-advocacy. A striking example of such associations has been the position that parents have occupied in a number of the self-advocacy organisations in different countries. Another issue which was explored in some depth was that of the supporter’s role, and some interesting comparisons arose throughout the course of the seminar, with regard to the precise nature of the user and supporter relationship, and the implications that this has for self-advocacy.

The last section will attempt to draw out some of the theoretical debates which emerged from the seminar, and will report upon some of the ideas that were offered as alternative ways in which to look at self-advocacy and its history beyond the social model.

### **Examples of Collective Self-Advocacy**

A number of interesting issues arose from papers which explored examples of people with learning difficulties coming together and working as a group (albeit to varying degrees of formalisation).

Papers which discussed the emergence of a self-advocacy group raised the subject of origins. It was interesting to reflect upon the *who?*, *where?*, *why?* and *when?* questions when considering the beginnings of organisations in different countries. In Japan and the Czech Republic, for example, self-advocacy grew out of parents' associations (in 1991 and 1997, respectively), and the decisions taken by those parents to develop a self-advocacy wing. Frank Bylov (University of Copenhagen) explained that in Denmark, although professionals in special education and social care had been encouraging self-advocacy around cultural activities for people with learning difficulties for a number of years, it was the Danish parents' association who initiated the first formalised (and eventually politicised) self-advocacy group in 1987. In Britain however, People First was established by users and supporters following an international conference on self-advocacy in 1984, although it was emphasised that others examples of self-advocacy were underway from the 1970s and were developing among people with learning difficulties within services.

The issue of funding for self-advocacy organisations was also discussed, and again, revealed some interesting peculiarities. Although government funding is common (for example in the UK, predominantly via Direct Payments, Lottery funding and local authorities), a number of organisations also rely on financial support from parents' groups (Japan, Austria). Some other complexities surfaced. In Denmark, the government agrees to fund the national self-advocacy organisation, but smaller groups often rely upon the goodwill of their local community. Griet Roets (Ghent University) explained that in Belgium, the government has recently agreed to contribute financially to self-advocacy groups, on the premise that the groups maintain their

existing links with universities, and student volunteers. Supplementation from European funds is also a common occurrence. However, to date it has developed under the wing of a university. The implications of these different funding streams upon user groups could provide an interesting area for further exploration.

The seminar also explored the issue of whether local self-advocacy groups have developed into wider national organisations. Where a country has been able to establish a national umbrella group (Denmark), what factors have influenced this development? Frank Bylov argued that in Denmark, self-advocates and their supporters believed that the power of combined action and the coming together of shared experience (through a national organisation) would enhance the strategic power of the self-advocacy movement to influence change. But why have not more national self-advocacy organisations emerged? What tensions are at play that might hinder such a development in other countries? And are we right to assume that a national self-advocacy organisation is either necessary or suitable for self-advocates in different places?

What do self-advocacy groups aspire to do? What activities are they involved in, and has this changed over time? Groups have various concerns, peculiar to their local area, as well as in the context of national policies. It seems that this informs the actions that self-advocates engage in. However, some patterns affecting aims and activities did emerge at the seminar, which demonstrate some international parallels. Notably, it seems that self-advocacy organisations are following quite similar phases of historical development (although groups are arriving at the different stages in varying periods of time) which directly influence their actions. For example, we heard from Eiji Tsada (Kobe University) that relatively young groups are making decisions which affect their recreational time in Japan. In the Czech Republic, Jan Siska (Charles University, Prague) explained that groups are exploring in more depth the process of 'speaking up', for example, through sharing life-stories, and discovering what self-advocacy can mean to them. From Central England People First and Jan Walmsley, we learned that as groups become more established, examples arise of self-advocates developing aims to reform services through research projects and training activities. From Denmark, we discovered that the self-advocacy movement is now beginning to claim political agency, and this is beginning to be mirrored by the small,

but growing group in the Czech Republic. Although such developments are not straightforwardly linear, nor representative of all self-advocacy groups, it was interesting to hear at the conference how many similarities did exist.

### **Personal Accounts of Self-Advocacy**

A number of life-histories were presented at the seminar, which revealed not only that self-advocacy has occurred outside formal groups and organisations, but that many of the personal experiences which led people to 'speak out' in different countries were remarkably similar.

Stories from England, Iceland and the US all focussed much attention on life in institutions, and the practice of 'self-advocacy' as a means of survival. It seems that despite variances in the types of institutions people were placed in, there was a shared experience about the loss of freedom and the need to assert some form of personal control. From different countries, we heard how people defended themselves against the institutional system, often in ways quite akin to one another. As Anne Lewthwaite's life-story (presented in conjunction with Sue Ledger, Open University and Lindy Shufflebottom, Yarrow Housing, UK) and Eyglo Ebba Hreinsdottir's life-history (presented alongside Gudrun Stefansdottir, Iceland University of Education) demonstrated, running away, hiding, and 'challenging behaviour' were all protest actions, and demonstrated to the audience how people with learning difficulties have been practicing 'speaking up' before the official self-advocacy story in each country begins. Other forms of resistance discussed at the seminar included one self-advocate adopting a different persona for inside and outside the institution, whilst another refused to speak at all. Self-advocates at the conference exchanged their personal experiences of resistance in institutions, or referred to friends' actions which echoed other examples of self-advocacy that were discussed. We also heard about people exercising their right to speak up against powers outside of the institution, most notably in the case of an individual upholding her right to refuse recommended sterilization by social services (continuing policy and practice in Belgium today). The point was made by Eyglo Ebba Hreinsdottir that the first wave of people with learning difficulties leaving institutions and embarking on new lives in the community should

also be thought of as ‘pioneers’ of the new services, alongside the many professionals to whom this term has been attributed.

Most examples of personal self-advocacy documented at this conference came directly from the narrative of self-advocates themselves. Papers from speakers such as Mabel Cooper with Dorothy Atkinson (Open University), illustrated that life-histories can be a means of people asserting a voice within and beyond their own communities and this is being practiced in many different countries. People speaking and writing their life histories, and others listening to and reading them can have a two-pronged effect. As Rannveig Traustadottir (University of Iceland) argued, not only do the stories reveal instances of self-advocacy in otherwise unexpected places, but the act of communicating the narrative itself has become an integral part of the development of self-advocacy, trans-nationally. Another paper by Herman Meininger (University of Amsterdam) discussed the increasing interest in using life-stories as a means of informing health and social care practice in Holland, in order for professionals to gain knowledge of the user outside the ‘functional’ framework<sup>1</sup>. Some concerns were raised at the seminar that this process could leave users vulnerable if the narratives were not treated by the system in a sensitive and appropriate manner. But the conference emphasised that the telling of life-histories by people with learning difficulties has underpinned many of the beginnings of self-advocacy action in different countries. It may also be emerging as a means of contributing to a collective voice for people with learning difficulties across national boundaries.

### **Relationships and Networks**

Another leading theme arising from the conference was the respective roles of people without the label of ‘learning disability’ within and outside the self-advocacy movement. Issues that were deliberated included: What is the nature of the relationship between the self-advocate and the supporter? To what extent have self-advocacy groups allied themselves with or consciously distanced themselves from

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<sup>1</sup> See Helen Hewitt *Identities in Transition: Formulating Care for People with Profound Learning Disabilities* (Unpublished PhD thesis, Loughborough University, 1997) and ‘A Life Story Approach for People with Profound Learning Disabilities’ in *British Journal of Nursing*, Vol. 9, No.2, pp. 90-95

others, such as parents and professionals? How have these networks and exchanges changed throughout self-advocacy's history, and what are the considerations for the future?

Interesting international comparisons were made between who takes the role of the supporter in different countries. In some instances, the supporter is employed by the self-advocacy group (UK). The employee's role may have a wide remit, including general administrative support, as well as a specific advisory function in research projects. Elsewhere, many supporters are student volunteers (Czech Republic and Belgium), and in Japan, it appears that parents remain closely tied to the self-advocacy group in their role as advisors. What implications has this had for the development of self-advocacy in different countries? Eiji Tsada argued that the domination of parents as supporters in Japan was making it more difficult for self-advocacy to move from an advisor-centred group, to a user-group. But as we heard from a British paper presented by Rohhss Chapman and Louise Townson, the position of an employed supporter within a self-advocacy group still presents many complexities. To what extent is the user-supporter relationship an equal one? Is there a pressure in some countries (contrary to the situation in Japan, for example) for the supporter to exercise complete impartiality within the relationship (and has this worked?). Trust and friendship were highlighted as being integral features of a successful relationship, which can bring many advantages to both parties. It was argued that equality comes from mutual respect, and from accepting that some mistakes may be made along the way.

Particular concerns were raised about the role of the advisor in research activities, and at what point the research moves from being 'person-led' research (with users in full control of every stage of the research process) to 'rejected' / 'rejecting' research (when the supporter intervenes and begins to dominate the project). An interesting debate ensued, with people examining this premise, and questioning its implications both for learning disability research, and for the user and supporter relationship. For example, can a person without the label of 'learning difficulty' contribute to the research dialogue on learning disability issues, without being in partnership with users? Is it appropriate for a non-disabled researcher to initiate and facilitate an inclusive research process, but continue to direct the overall thrust of the research

agenda? It was agreed that within inclusive research practices, it is imperative that both users and supporters are honest about the nature of the research partnership, and reflect upon its implications for them as co-researchers.

We have already seen how parents across Europe and Japan have played multiple roles within the development of self-advocacy, including establishing groups, contributing funds, providing initial support, and in some countries, retaining a dominant advisory role. This has produced a variety of tensions, and is the source of some conflict within the movement. From Japan, we learned of the speaker's frustration in his role as supporter, brought about by the unwillingness of parents to allow self-advocacy to move beyond recreational matters, towards other issues such as services, empowerment and independence. However, in contrast, we also heard about parent-user alliances in some papers, which disrupted the perhaps more common assumption that the position of parents in the history of self-advocacy has always been problematic. These included some personal reflections on invaluable alliances, such as of the combined power of a user, her mother and her support worker in fighting the recommended decision of social services to sterilize her (Belgium). The self-advocacy movement in Denmark is a notable example of more formal links between self-advocates' parents being forged, on a national scale. A process of negotiation has occurred between the different parties in which tensions have been acknowledged and contested. The result has been an acceptance (by many on both sides) of the strategic advantages for people with learning difficulties to work with parents towards common objectives and collective empowerment.

### **Theoretical Frameworks**

A number of papers at the conference engaged with some of the theoretical debates which can enrich our understanding of self-advocacy and its history, within an international context. Different models were put forward as possible theoretical approaches to the subject of self-advocacy, and some of these ideas were explored further among the audience.

In one paper from Belgium, Marijke Goedgeluck (self-advocate) and Griet Roets ('ally') positioned the self-advocate's life-story in a pluralist feminist and post-modernist framework. The paper was designed to demonstrate how the female self-

advocate's experiences can be understood both in terms of her 'otherness' as a woman, as well as someone with the label of 'learning difficulties'. The paper also explored how narrative can be used to expose the power dynamics between service users and professionals, and how the unfolding of a life-story can 'reclaim resistant discourse over oppressive discourse'. Interestingly, the paper also engaged with the relationship between the user and her supporter, deliberately positioning the two women into a 'pluralist feminist ethnographic account'. It explored their relationship as co-researchers, and examined the implications for women as subjects in dialogue, through an analysis of the narrative account. The paper reflected upon more traditional constructions of self-advocacy and the interplay of such interpretations with gender discourses.

Frank Bylov's paper offered an interesting model of the historical development of self-advocacy in Denmark, but this typology may be a useful way of examining parallel developments in other countries. The speaker explored the notion of 'generations' within the self-advocacy movement, which have occurred in three phases in Denmark. First, we can see the origins of self-advocacy in terms of a movement *for* people with learning disabilities. Second comes the generation of a movement *with* disabled people. The third generation of the movement witnesses the development of self-advocacy *by* people with learning difficulties. The respective generation has implications for the activities and objectives pursued by the movement at that time, the roles of a multiplicity of actors (within and outside) of the movement, and the capacity of the movement to claim political agency. This typology is by no means a rigid construct from which to analyse the history of self-advocacy in each country. However, as discussed above, the seminar did illustrate self-advocacy movements across nations displaying similar patterns of development, and therefore the notion of 'generations' could be an interesting framework from which to investigate the evolution of self-advocacy in different countries.

Eiji Tsada's paper, discussing the history of self-advocacy in Japan, raised another important theoretical debate. Although many of the self-advocacy ideas in Japan have been exported from the West, the speaker argued that significant features of the movement such as independence and self-determination were struggling to take hold. He attributed this to such concepts not being culturally valued within Japan (both in

and beyond the realm of learning disability), and suggested that this was one explanation for the continued reluctance of parents to give more power to self-advocates. The speaker argued that the 'independence' model, so integral to self-advocacy rhetoric, in practice may not be appropriate in Japanese culture. Instead, an alternative 'interdependence' paradigm was put forward, in which a more collaborative relationship between users and advisors can be constructed. Whilst it was acknowledged that conflict will be inherent in such a model, these tensions were welcomed as a useful way to begin the creation of more honest and equal relationships. There was some debate about whether the cultural values supposedly particular to Japan were so different from the experiences voiced throughout the conference in other nations (for example, emphases on family, relationships, trust and anxieties around allowing children to become more independent), and therefore the framework of an 'interdependence' model within self-advocacy was discussed as a model which may have wider relevance beyond Japan.

Some of the themes outlined in this report of the conference have been addressed in the existing literature; others are quite fresh to the studies on self-advocacy. The immediate result of the seminar has been a deepened awareness amongst participants of this rich and complex unfolding story, both in national and international contexts. It has provided an excellent foundation for further research on any one of the above issues, which will stimulate knowledge for all those involved in the self-advocacy field. Importantly, it has also afforded researchers an opportunity to create new networks and build on existing ones, facilitating more international comparative research activity into self-advocacy.

Liz Tilley  
School of Health and Social Welfare  
The Open University