Disability Organizations in the Regions

Kate Thomson

The literature indicates that the development of civil society can have an empowering effect on citizens and promote change. Within the realm of welfare, proponents of welfare pluralism point out that the involvement of voluntary sector organizations may have a positive impact on service delivery and policy across the sector (Mayo 1994, 22; Green 1996). This chapter describes the activities of nongovernmental organizations concerned with disabled children in two Russian cities. Following the conceptualization of civil society outlined in the introduction—that is, civil society as a space of collective activity by citizens that can promote political change or continuity—the chapter explores the extent to which disability organizations have the potential to promote "bottom-up" change in the local welfare sphere.

Theoretical Context

State–Voluntary Sector Relationships

Interest in and analysis of voluntary sector involvement in welfare takes a number of approaches, outlined and categorized by Salamon and Anheier (1998). What they term "government failure" approaches (alternatively named the "vacuum hypothesis" by Westlund and Westerdahl 1996, cited in Sätre-Åhlander 2000, 446) indicate that the voluntary sector can contribute to the overall welfare sphere by "gap filling"—that is, providing goods and services that state welfare structures fail to provide. In the case of Russia, glaring "gaps" in Soviet state welfare provision had been exposed over the years preceding the end of Communist Party rule (Mcauley 1991, 207). Any agency acting to plug some of those gaps might be welcomed as a positive force. A slightly different perspective on "government failure" would assert that voluntary involvement in welfare is preferable to state involvement in and of itself: that voluntary sector welfare provision is morally superior to that of the state (Green 1993; Kidd 2002, 330). In cases where the state has been indubitably discredited as a provider of welfare services, as happened in Russia from the glasnost period of the late 1980s, this view holds an element of potency for writers from across the political
spectrum. This can be combined with a more general sense that the voluntary sector is a desirable element of “civil society,” a building block of truly democratic societies, which needs to be nurtured in both West and East (Keane 1988; Powell and Guerin 1997; Salamon 1995).

It is not essential to take a moralistic, either/or position on voluntary versus welfare provision, however. Many writers, rather than assuming conflict and competition, expect cooperation and partnership between state and voluntary sectors—an interdependence approach (Salamon and Anheier 1998, 224–25). In practice, empirical studies worldwide have tended to demonstrate that state–voluntary sector relationships in this sphere are often of a cooperative, interdependent nature.

This chapter explores concepts around state–voluntary sector relationships in the welfare sphere in relation to four case study organizations working in the area of disability in Russia. The organizations’ role as “gap fillers” is assessed in the local context of relevant state service provision. Relationships between the organizations and state structures are explored in some detail. Although the study revealed a variety of relationships between state and voluntary sector organizations, the chapter ultimately concludes that “interdependence” provides the best descriptive and normative base from which to analyze such organizations’ development. State structures were found to have an ambiguous but often facilitative role in the development of effective civil society organizations in this sphere, even where those organizations’ role included challenging state policies and provision.

Disability

In addition to the concepts around state–voluntary sector relationships, a second theoretical strand running through the evaluation of service provision is provided by the social model of disability (sometimes termed the “civil rights model”). This is an approach that draws a distinction between impairment (a defect in the biological mechanism of the body or mind) and disability (a disadvantage created by social organization and attitudes) (Oliver 1990, 11). The focus is on social structures that serve to effectively disable people who have mental or physical impairments.

The social model is in opposition to the individualized models of disability prevalent in industrialized cultures. One indication of the individual approach is medicalization (ibid., 43), which focuses only on the impaired or “abnormal” body or mind as the source of disablement: “to be defined as a ‘flawed’ body is simultaneously to be defined as incapable of adequate social participation” (Hughes 2002, 60). Segregation from “normal” social structures has often been a consequence of being labeled disabled or defective; treatment and “repair” of the flawed organism is also emphasized above all else. “Personal tragedy” theory is another aspect of the individualization of disability, emphasizing charity, pity, and “compensation” as appropriate responses (Oliver 1990, 1–3).

The social model approach is a critical one that seeks to expose and challenge the way that those individualized accounts inform social attitudes and institutions. Analyses based on this approach are human rights-based and assume the need for material change to social structures in order to reduce or eliminate oppression. Disabled people are presented as an oppressed minority, aligning the approach with feminist and antiracist standpoints: “as in the cases of women and black people, oppressive theories of disability systematically distort and stereotype the identities of their putative subjects, restricting their full humanity by constituting them only in their ‘problem’ aspects” (Abbey 1997). Civil society organizations that potentially are effective in terms of this approach therefore parallel movements of other oppressed groups in presenting a “politics of difference” that challenges structural inequities (Young 2000, 81–120).

One aspect of challenging social constructions of disability—including those maintained by state structures—might be the articulation of new and more positive identities for what was a previously hidden and stigmatized group. In the context of this chapter, therefore, the social model approach forms a background for identifying “gaps” or injustices in state services that might be filled or challenged by civil society organizations and for assessing how effective existing organizations have been in meeting those aims. In so doing, however, the chapter also highlights the difficulties of applying this inherently “Western” political and analytic approach in the given context.

Background

The Study

The empirical research on which the chapter is based was carried out in 1998 in the cities of Samara and Saratov, both large regional centers in European Russia. Exploration of voluntary sector activities took place within the wider framework of a project investigating the range of services and support across all sectors for people with learning difficulties (mental retardation). The study indicated from an early stage that state provision of services for this group was lacking; both in its scope and its approach: there were definite gaps that required filling. As well as state activity, the activities of the voluntary and informal sectors (i.e., care provided by family and friends) were examined to provide a fuller picture of the welfare sphere.

All the material presented here was collected through interviews with organization heads, and sometimes with other members or officials. It was supported in most cases with documentary data such as publicity materials and organizational records. There were also opportunities to observe the workings of the organizations by attending meetings or other events. The chapter is informed as well by the other elements of the study—that is, by interviews, documentary data, and observations from state sector institutions and professionals and by parents or other informal caretakers of disabled people.

Local Welfare Context

To identify a possible need for civil society organizations in the case study areas to fill gaps or challenge injustices, a brief outline of state structures and services relevant to people with learning difficulties is required.
The most relevant state services inherited from the Soviet era targeted at children with learning difficulties were the special schools system and long-stay residential institutions. Special, or auxiliary (vспомогательные, nye), schools represented a part of the Soviet educational and welfare system in which there was much pride (see McCagg 1989; Foreman 1997; Thomson 2002a). One category of school was for children with mild to moderate learning difficulties who were regarded as “educable.” This school system was still in place in both the cities studied, and there was a mix of day schools and those with boarding facilities within the cities. The school system had changed very little, despite evidence of professional engagement with “Western” models of special education—for example, the ideal of integrated education (see Thomson 2002a).

The social model of disability regards any form of “special” education as oppressive. Such systems set disabled children apart from others, thereby locating the “problem” within the children rather than considering that the mainstream education system needs to be challenged to become inclusive of children who have impairments (Oliver 1996, 78). The Russian system was distinguished by its very high degree of segregation or differentiation between children based on the perceived type and degree of impairment (Thomson 2002a). Service provision was driven by an apparently “scientific” system of defining what kind of organic impairment children had. It therefore presented a child-deficit, medicalized understanding of impairment and disability. Furthermore, the system was very much geared toward those children deemed most intellectually able; those who had mild or moderate learning difficulties were relatively well served in the special schools system. Children with more severe impairments were explicitly excluded even from the special education system—the only provision for them was in the form of long-stay residential institutions.

Residential institutions for children with more severe impairments (those regarded as “undeniable”) were usually located outside the cities, in rural or semirural areas. These provided varying educational input depending on the residents’ perceived degree of impairment. Young adults often moved on from these facilities to adult “psychoneurological” institutions. The system often therefore involved disabled people being effectively segregated and institutionalized for their entire lives. Many parent informants in this study regarded the institutions as a dreaded last resort, although many also reported being advised by medical professionals to place their children in this system from infancy. The institutional and educational systems therefore separated disabled people both from nondisabled people and from one another on the basis of impairment category. This kind of segregation, or “fragmentation” (Vernon and Swain 2002, 92), has formed the cornerstone of analyses of disableist oppression.

Although the old state services had changed little, there had been some development of new state services in both Samara and Saratov in the post-perestroika period. This reflected national directives regarding service provision for disabled children and other vulnerable groups. New community-based services (Thomson 2002b) included “rehabilitation centers” for disabled children. In Saratov the main new rehabilitation center was primarily a residential facility used by children from all over the oblast. Samara had four relatively new centers offering a variety of services: one operated mainly as a preschool facility for disabled children; another provided recreational activities as a kind of after-school club, as well as therapeutic interventions; and yet another was set to operate as a preschool facility as well as offering residential periods for other children. Overall, Samara’s rehabilitation center network was more diverse, covering a greater number of children with diverse needs, and was therefore more inclusive in the broad sense.

The rehabilitation centers offered a more inclusive, integrated approach to services for disabled children than that offered by the special schools or residential systems. Those children living in the community (rather than in institutions) who could not access schooling due to being regarded as too severely disabled could make some use of the centers. However, such contact was not always regular or frequent. Perhaps inevitably, since they called on the same pool of professionals and had to complement the system in some way, the centers drew on the terminology and practices of the special education field in defining their work and the type of children they served. They increased the scope of state services, filling certain systemic gaps and addressing previously unmet needs, without challenging radically the approach to children with learning difficulties.

Another part of the community-based social services initiative was the social service centers that were provided at the level of city district. They offered access to social workers and other relevant professionals able to dispense advice and in some cases material support. One of the vulnerable groups catered for by the centers was disabled children. The centers represented a sphere of activity and an accessibility that was lacking in the Soviet welfare system, although their direct contribution to the welfare of most families and children who participated in this study was marginal.

In both sites of study, the main gaps or injustices in state welfare provision for children with learning difficulties involved access to education for more severely disabled children and availability of longer-term services that did not entail separation from the family and community. State authorities were not entirely unaware of these problems, as can be seen from the service developments that had happened in the years leading up to this study. These developments were contingent upon local decision making and resources; in Samara the expansion of community-based services for disabled children had occurred more rapidly and in a more diverse way than in Saratov. This provides an interesting backdrop against which to assess the gap-filling or interdependence theses of voluntary sector activity: were organizations more active or effective in Saratov, where gaps were greater, or in Samara, where state institutions had more obviously committed themselves to making changes and were therefore, perhaps, more cooperative with civil society efforts?

Case Study Organizations

Voluntary organizations were identified through personal contacts (for example, with people working in state services) and publicity materials. Overall, three relevant organizations were identified in Saratov and four in Samara. There were few
nongovernmental bodies in Saratov and Samara currently offering "services" to people with learning difficulties. This reflected, more than anything, existing voluntary organizations' operational capabilities; it also accorded with the national pattern of voluntary sector development, in that indigenous service organizations are relatively rare (Pestrikova 1998). The present study found only one case of direct service provision for people with learning difficulties by the voluntary sector, and this was an international rather than an indigenous body. With this one exception, the organizations did not form part of the dynamic, new, internationally funded third sector: their activities were small-scale and chiefly of a charitable or advocacy nature. I have selected two organizations from each city as case studies. Although the study as a whole explored the position of children and adults with learning difficulties, the four voluntary sector organizations selected as case studies here were all involved with disabled children. This is a fair reflection of the emphasis on children within state policies and provision and of the lack of organizations that focused on people with learning difficulties as opposed to disability in the generic sense. In each city, the local organization most active in the relevant sphere was selected for case study. The other two case studies are provided by the respective local branches of a national network of organizations, which provide interest because of the contrasting fortunes of the two branches.

Saratov

The two case-study organizations from Saratov are the Children's Fund and First Step (Pervyi shag). The Children's Fund was the regional branch of a national charitable organization that had been established in the late 1980s as an official initiative to tackle child-related social problems, of which there was a growing awareness at the time. Its projects concerned children in general, primarily those from disadvantaged families or living in state institutions. In the past, the Saratov branch had carried out a number of projects involving disabled children, including those with learning difficulties. First, it provided material assistance and social and cultural outings for children living in residential institutions and for children with severe learning difficulties. It also offered more community-based projects such as a drop-in advice service for families, a "parents' school" for those whose children had disabilities, and a parallel social club for their children. The Fund frequently hosted social functions for disadvantaged children and their families, usually in partnership with the state social service centers. Local children registered as disabled and those attending special schools would be invited.

Modest forms of material support for the Fund's activities came from the state and local businesses. For example, local government waived rental fees on the office accommodation. Support for specific activities was often sought through established contacts in the business world (Children's Fund [Saratov], interview 1998a). Effectively, methods of extracting charitable donations had changed little since Soviet times when enterprises were expected to fulfill their duty to the local community by supporting schools or other institutions. Such "donations" rarely took a monetary form; many social and economic institutions at this time were running on a virtually cash-free basis, or what Woodruff (1999) calls the "barter of the bankrupt." Instead, donors would offer the use of facilities or materials that they did have available. Although it cannot be regarded as resource-rich, the Fund was able to make extensive use of established personal and institutional networks to provide some support for its activities. This included links with local media. For example, at the time of the study an appeal for books was being presented on local television for the Children's Fund project of stocking libraries for child residential facilities. First Step was a self-help association of families with disabled children. It provided a supportive forum for discussion and advice on services and many other areas of life; it did not provide direct services or charitable assistance. Despite its profile, First Step was not a grassroots organization in the true sense. Its creation was not the initiative of parents but of the social worker responsible for disability issues in the city's central social service center. She had made the initial links between parents and organized the first meetings (Central Social Service Center, interview 1998). This relationship continued as the center informed eligible parents about the organization's existence, and some meetings were held in a room provided by the center. Members were also gained through the city's rehabilitation center where the chair of the association worked as the chief doctor.

Samara

The two Samara case study organizations are the Samara branch of the Children's Fund and the Association for Disabled Children. Samara's Children's Fund was far less active than its counterpart in Saratov; while practically every interviewee in Saratov referred me to the Fund, several in Samara claimed that it was defunct. The resources—both material and human—at its disposal appeared to be far more limited, and its activities by 1998 were mainly restricted to the relief of material hardship, such as distributing donated clothing and other goods (Children's Fund [Samara], interview 1998b).

The Samara Association for Disabled Children was made up of parents and professionals, and its chief activities focused on support and services for children who were deaf or hearing-impaired. It was included in this study, however, because it spoke out on all disability-related issues, and because its services were not exclusive to hearing-impaired children. It was created in the same period as the national Children's Fund and was similarly formed by "official," although not governmental, figures—health and welfare service professionals and journalists. In 1991, the association had set up and run the city's first children's rehabilitation center. After a year, the operation of the center was transferred to local government, which matched it with three more rehabilitation centers in the city (Association for Disabled Children, interview 1998). The association had a lay membership of parents, mainly recruited through the rehabilitation center with which the organization was still closely associated.
Voluntary Organizations as Agents of Change

Shaping the Welfare Sphere?

One of the aims of this chapter is to assess the success or potential of the voluntary sector organizations to act as agents of change in the local welfare sphere—could they plug gaps or address injustices created by state structures? All four case study organizations had close historical or ongoing relationships with state bodies, although this relationship was sometimes bound up with problems. Despite operational and structural limitations, some of the organizations could be seen as effecting change.

The most “active” organizations were active chiefly in a social and advocacy sense, rather than providing services in the usual sense. They offered meetings places for families who had disabled children and alerted the relevant state authorities to particular problems faced by young disabled people and their families. In this latter sense, and in some more concrete examples, it is possible to pick out examples of organizations that had acted as change agents in the local service provision sphere. Where this had happened, the nature of relationships with state structures can be seen as crucial.

As an “official” charity in the 1980s, the Children’s Fund’s origins were in the “ambiguous zone” between the worlds of government (“bureaucracy”) and the voluntary sector (“associational” world) (Billis 1989). In its early period, the Fund was instrumental in persuading state agencies to make policy and provision changes to address children’s issues (White 1995, 169). Some important, even radical, initiatives were produced that became established parts of governmental welfare provision—for example, the community social service centers mentioned above. The Fund’s development might be seen as a good example of the potential for civil society institutions to shape and facilitate change to state systems through a relationship of interdependence. However, this very lack of definite autonomy from the state reduced the integrity of the Fund in certain quarters at a time when state provision for disabled children in particular had been discredited. At the national level, even in the Fund’s early years, criticism in the press focused on this ambiguous role (Waters 1992; Harwin 1996). There is a credibility dilemma here, raising the question of whether an organization can meaningfully challenge state structures while relying on them to maintain its own status.

In both Saratov and Samara, the Children’s Fund began the advice-related and charitable assistance work that had largely been taken over by state community social service centers. Historically, then, these organizations had shaped the welfare sphere, albeit as part of a national project. The head of the Saratov Children’s Fund explicitly stated in an interview that it was still their role to innovate, and that the state was expected to take over the administration of successful projects (Children’s Fund, interview 1998a). As Salamon and Anheier (1998) point out, in running services taken over from the voluntary sector, the state is to some extent dependent on that sector for its knowledge and expertise—an aspect of interdependence. The Saratov branch’s innovations were on a much smaller scale than in the past, but its expertise was still recognized and valued by local state structures. By contrast, at the time of the study the Samara Children’s Fund had a much less productive relationship with the state. The director stated that there was currently no cooperation between the Fund and the committee in charge of social services development in the region, citing a lack of will on the part of the committee (Children’s Fund, interview 1998b). Its involvement and influence in state welfare service provision and even in charitable provision generally had waned significantly. This role, particularly in the area of disabled children, had been assumed by another organization—the Association for Disabled Children (ADC).

All four case study organizations were to a large extent dependent on the favor of the local governmental sector for accessing resources, even though there was no direct funding relationship. Three of the organizations had permanent administrative accommodation that was subsidized or provided by the state: rental was waived for the Children’s Fund in both cities, and the Samara ADC used as its base the state rehabilitation center of which the association head was director. Organizations were able to use state links to access additional resources. Close relations to state bodies gave organizations some cachet and opened the door to material support—albeit limited—from local benefactors and commercial organizations. Those with the strongest links were able to pass on this advantage to smaller organizations. First Step, for example, maintained a good relationship with the Children’s Fund in Saratov: one of its most active board members was involved with the work of the Fund on a voluntary basis. This relationship was instrumental for First Step, because the recommendation or intervention of the Fund head could open doors to support from commercial bodies and from the state (First Step, interview 1998).

First Step also had more direct links with the state sector, which facilitated one of its chief aims, to represent the interests of parents within the local state welfare authorities. For example, the social service center’s disability co-coordinator (who set up the group) took an active part in some meetings. This offered the opportunity for information sharing and discussion of services and benefits, about which she had expert knowledge. Observation of meetings with and without this official indicated, however, that her presence as an “expert” inhibited the discussion somewhat. For example, decision making processes in the commissions, which made recommendations for educational provision based on assessments of individual children, were discussed at length in a private meeting (April 1998). When concerns about favoritism and “political” judgments affecting commissions’ decisions were raised at a meeting held in the state facility (May 1998), the official quashed them as not meriting discussion. Another direct state connection for First Step was that the association chairperson was head doctor at the oblast rehabilitation center. He was a true member in that he had a disabled son, and his status must have given the association credibility with other professionals. However, this affiliation clearly limited the organization’s inclination to push for change in the rehabilitation service. Thus, while affiliation with state bodies lends credibility to an organization, this very affiliation potentially inhibits its effectiveness, allowing for some control from state bureaucracy. White (1995, 168) neatly sums up this difficult balancing act: “the desirable situation was of course
to be simultaneously immune to pressure from the party-state authorities while being able to influence the latter.”

Reliance upon state relationships for resources, including private donations, can in theory compromise the self-determination of voluntary organizations, producing what Salamon and Anheier (1998, 225) term “philanthropic paternalism.” Furthermore, for theorists who regard the voluntary sector as necessarily superior to state welfare provision, such a lack of real autonomy from the state might be regarded as problematic. In context, however, this genuine interdependence between the sectors with regard to credibility and resources is very understandable. The Russian voluntary sector had been marred by corruption scandals; from the perspective of donors, official connections guaranteed that donations and sponsorship agreements were “safe.”

What determined the closeness and effectiveness of organizations’ relationships with the state? How could organizations play a key role in the local welfare sphere? For the case studies, personal connections appeared to be very important. A “family connection” between the Saratov Children’s Fund and the local administration was claimed by one respondent to explain the relative inactivity of Samara’s Children’s Fund compared to Saratov’s (Anonymous interviewee 1998). This is certainly a very plausible explanation for the degree of cooperation with administration and the authority that the Fund enjoyed in Saratov: family and life history links are ones that may still be appealed to in order to make things happen in the “new” Russia (Lonkila 1997; Ledeneva 1998). Similarly, the head of the Samara Association for Disabled Children was able to utilize her presence within local networks as the director of a state rehabilitation center to maximize the ADC’s profile. These connections served the respective organizations well. However, the fact that they were based on existing relationships does not bode well for the development of a truly diverse voluntary sector.

The nature of the state structures themselves, providing the local institutional background against which voluntary organizations were attempting to work, was another important factor determining the degree of mutual influence. In Saratov, there was a State Committee for Cooperation with Voluntary Organizations, which appeared to make a real difference to the way that the two sectors cooperated, even if this applied only to certain state-approved organizations—in important in this context, the Children’s Fund. Conversely, the different administrative structures in welfare services in Samara—the existence of a single new body, spearheading changes to disability services—may have had an impact on the perceived need for action from the voluntary sector. Although there were calls for change in state disability services from voluntary sector organizations, parent and professional interviewees in Samara generally appeared to feel rather more satisfied with services available than those in Saratov: while still full of gaps and bureaucratic obstacles, by comparison they offered a significant amount of variety.

Shaping Responses to Disability?

The previous section discussed the organizations’ presence within and practical impact upon the local welfare sphere. The chapter now turns to an exploration of their ideological impact. Did they challenge dominant constructions of disability/learning difficulties? Were they offering a “politics of difference” or articulating new identities?

Addressing Injustices

The earlier discussion highlighted certain gaps and inequities in the operation of the state welfare system for children with learning difficulties. Did the voluntary organizations recognize these injustices, and in which ways did they address or draw attention to them? A key area of concern was the special education system, which was highly differentiated, or segregated, on the basis of impairment and effectively excluded or disadvantaged a significant number of children. Only one of the case-study organizations—First Step—was closely concerned with, and vocal in its criticisms of, special education. This largely reflected the parent membership’s concerns. However, the members were challenging not the fundamental principles of the system, but its shoddy, arbitrary administration. Specifically, there were protests against the erroneous, sometimes apparently malicious, categorization of children and the consequential detrimental effect on their access to educational provision (First Step Organization Meeting, interview 1998). First Step was suggesting a way of addressing some of the problems in the system, advocating the development of a new school for children labeled as having severe learning difficulties. Some children excluded from existing schools on the basis of severe impairment would therefore be able to remain in the system (First Step, interview 1998).

In Samara, the Association for Disabled Children also proposed a new kind of special education institution: a training institute incorporating a sheltered enterprise for young people graduating from special schools. It did so in the context of a November 1998 conference on vocational and professional education for disabled young people, attended by statutory and voluntary sector representatives. The “problem” in this case had therefore already been recognized by those in the local state sector, and the organization’s position was suggestive rather than confrontational. In neither of these examples were the organizations radically challenging the special education system. Rather, they were demanding the system’s expansion to include more categories and types of institution. This is a position that could be criticized from a Western social model perspective, which regards any form of segregation as oppressive.

These suggestions can in their context, however, be regarded as significant and reflective of immediate, legitimate concerns of parents and professionals. Parents in First Step, for example, were challenging the “oppression” of some children’s total exclusion from the education system. The urgent priority, understandably, was that these children should have access to education. In this context, demanding the dismantling of the special education system in itself can be seen as a rather distant luxury. The Samara ADC’s proposals for postschool provision were a response to the general socioeconomic situation of the time. Those already disadvantaged by impairment were more likely to be exposed to unemployment and other forms of material hardship. Given the lack of an effective social safety net for any members
of society, the creation of structures to protect a particularly vulnerable group of young people cannot be seen, except in the most rigid social model analysis, as a continuation of oppression.

The organizations were also in a small way addressing gaps and injustices for disabled children in the medical sphere. By and large, in so doing they complied with and even encouraged a “medicalized” approach. For example, the Saratov Children’s Fund’s work with disabled children was placed within its “Health” stream. The emphasis of services it offered for disabled children and their families was on cure and treatment: tutelage for parents on their children’s conditions and help for children within the psychiatric hospital children’s ward (Children’s Fund [Saratov], interview 1998a). First Step, the parents’ organization, included in its aims and objectives the “restoration of impaired functioning and skills” for disabled children (First Step 1997). Much of its supportive work with families involved providing information about treatments for certain conditions; the concerns of many of the members appeared to revolve around medical issues, such as obtaining medicines (First Step Organization Meeting, interview 1998).

In their criticism of the medical model, social model analysts tend to assume that appropriate medical treatments will be provided for disabled people when necessary; their concern is that disability should not be seen primarily as a medical problem (Oliver 1990, 48). The background to this study involve a health infrastructure that was truly in crisis; where access to appropriate interventions, such as drug therapies or physical rehabilitation, was severely restricted. Regarding children with learning difficulties as “sick” (boî’nye) can be unhelpful in shaping perceptions of the kind of support they might need. However, in their context, organizations that provoke discussion about access to necessary medical interventions or seek merely to improve experiences and meanings of medical treatment should be seen as representing legitimate and even challenging voices.

These examples highlight the tension inherent in applying an apparently universal, human-rights based model such as the social model of disability to a rather different economic, political, and cultural setting from that within which it was first conceptualized. Although useful in highlighting and exploring injustices or possible gaps in services, the very simplicity of the model renders it somewhat insensitive to different contexts and situationally appropriate responses.5

A Politics of Difference?

Voluntary organizations working in the area of disability clearly have positive potential to promote the rights of their members or “client” groups, and to articulate new and positive identities. The case study organizations were resisting professional definitions of disability (for example, in the medical and educational spheres) only in a very limited way. These groups did not regard themselves as having a “disability politics” agenda. However, we can identify some ways in which organizations were successfully empowering or promoting the rights of their target groups.

First Step, the Saratov parents’ association, offers the most obvious example of limited “empowerment.” By observing meetings (April–May 1998) and interviewing members, I could identify the association as having three distinct functions: emotional support, an information and advice service, and advocacy. The organization’s very existence promoted the sense that parents of disabled children could have a collective identity and voice. Encountering commonalities of experience was especially important—and potentially empowering—for parents, as the recent history of families of disabled children was one of isolation, silence, and stigma.

The meetings’ role as an information and advice source was met through exchange of experiences. Group members were able to arm each other with knowledge about rights and entitlements and on where to go (or sometimes, which person to speak to) to have them upheld. For example, one member would be aware of a strategy for avoiding a particular problem—such as a particular pharmacy that was willing to dispense free medicines to disabled children. In other instances, members would be able to clear up a point of procedure or entitlement about which others were confused. The importance of mutual support and information should not be underestimated; a developing awareness of “rights” in itself cannot be seen as anything other than a political perspective. Although advocacy was not regarded as a prime aim of the association, it did not shy away from bringing particular issues to the attention of the appropriate authorities—for example, the need for educational provision for children labeled “undeducable” and for transparent procedures to access certain benefits.

First Step was “empowering” parents of disabled children by providing a collective voice and a basic sense of solidarity. Creation of a legitimate and assertive voice for this group was particularly important in a context where some professionals still asserted in interviews for this study that parents of children with learning difficulties were themselves usually “sick” or dissolve. The coming into being of all four case study organizations, and their involvement in the sphere of child disability, indicates and encourages social recognition of the existence and rights of disabled children. In this sense the organizations might be credited with enabling the articulation of new and more positive identities by challenging, albeit indirectly, cultural constructions of childhood disability—including learning difficulties—as tragic and shameful.

Conclusion

The focus of the chapter has been regional and local. Indeed, these case studies from two separate localities indicate that local factors were paramount in determining the extent of voluntary sector activities and influences. National factors, which were significant in stimulating the original emergence of certain of the organizations, had become less important. Even the Children’s Fund, a supposedly national organization, had fragmented and was dependent on local sponsorship and cooperation. It is difficult, therefore, to generalize confidently on the extent to which this picture reflects a national one. It is by necessity a snapshot of the situation in the late 1990s that cannot alone form the basis of a prediction of the current and
future situation for these disability organizations. Nonetheless, through comparison of the fortunes of the organizations in two localities some generalizations can be made about the emergence of such bodies and their relation to, and impact upon, the state welfare sphere.

This chapter has assessed voluntary organizations' willingness and potential to change attitudes and practice on disability issues and to empower disabled people or their supporters. There had been changes in the state approach to, and resources available for, disabled children, and behind these changes some "civil society" pressure was identifiable. While a fully politicized approach to disability (in the Western sense) was lacking, there were signs that certain professional practices and social structures were continuing to be challenged. The organizations highlighted in this discussion acted as agents of change in the following ways:

- initiating welfare services later developed by the state sector;
- increasing the visibility of disability issues and disabled people;
- destigmatizing disability ("respectabilization"); and
- acting as bases for social support network growth.

As forms of change, these essentially move disability from the private into the public sphere, creating a space for disability issues in civil society.

Broad comparison of the two sites would point to the support of "government failure" or gap-filling theories of voluntary sector welfare involvement. That the profiled organizations in Saratov were more active and, sometimes, confrontational toward state bodies might be partly explained by the fact that fewer substantive changes had been made to state welfare provision in that city. By contrast, in Samara, the scope and availability of community-based state services for disabled children had expanded quite significantly over a small number of years. There was thus less of a sense of government failure—or the need for gap filling—in Samara than in Saratov.

However, in these cases, the notion of state—voluntary sector interdependence is perhaps even more compelling. One aspect of this is that key figures in the voluntary sector in both sites were "embedded" in enabling networks that centered around state structures. Moreover, the multidirectional nature of influences between the state and voluntary sector must be noted. The idea that the voluntary organizations (as aspects of civil society) might be able to effect change "from below" is, based on these examples, rather problematic. The case studies offered clear examples of organizations being mobilized on the basis of discontent with the status quo (in this case, concerning gaps or injustices in welfare provision for disabled children) and of this form of association having a direct impact on that provision. However, this mobilization had not typically taken place in an arena that can be truly distinguished from "the state."

Even First Step, the self-help organization profiled here, cannot be seen simply as a grassroots activist group rising in opposition to the state. It provides an interesting example of the apparently paradoxical tendency for state structures to consciously facilitate "activism" in the form of user groups, which is present in Western societies also (Acheson and Williamson 2001). That is, the state actively participates in what might be termed consciousness raising, kick-starting the transformation of individuals' views of their own situation, and generating a more politicized perspective that seeks change "from below."

State structures and relationships appear to have been deeply implicated in the development of the organizations profiled here, both in the origins of associations themselves and in their ability to act. To an extent this reflects "Soviet" patterns of enabling relationships and social action. Historically, certain of these organizations had been directly involved in important and undoubtedly positive developments in state provision for disabled children, and they continued to pursue this aim. However, this very closeness—and the apparent importance of that closeness for action and presence on the local scene—raises questions about these and similar organizations' ability to effectively provide a voice for excluded groups. Relations (or a lack of them) to state structures and professionals could restrict or compromise that voice.

Care must be taken however not to overemphasize the distinctiveness of these features of the Russian voluntary sphere; after all, the notion of "interdependence" of the state and voluntary sectors appears to resonate cross-nationally (Salamon and Anheier 1998, 224–25). Furthermore, the focus of this study on disability issues carries with it some expectation that civil society organizations will focus their activity on state provision. The very concept of "disability" is one that is essentially a category created and upheld by state structures and policies (Stone 1985). In the Russian case, organizations have had a natural orientation toward drawing attention to huge gaps and injustices in state policies and provision that could only be addressed through some interaction with relevant state bodies. Perhaps, serious improvements in the scope and inclusiveness of that provision, and the material resources available, would facilitate organizations' greater autonomy to focus on consciousness raising or "political" activities. To conclude, these organizations acted in a limited way as a force for change, albeit one that, paradoxically, could be traced back to state structures themselves.

Notes

1. The organizations' real names are used here; this is in accordance with the organizations' own wishes. However, individual interviewees and contacts within the organizations have not been named. Although organization heads' identities would be difficult to conceal, interviews and information were also provided by rank-and-file members or associates of the organizations. All interviews are therefore cited anonymously.

2. There were six "auxiliary" schools (now known officially as "special correctional schools") for children with learning difficulties in Saratov and eight in Samara. A few other schools within the special education system in the cities—for example, schools for children with hearing impairments, or for children with cerebral palsy—also accepted children with learning difficulties in special units. All these schools catered only for the more able children with learning difficulties; those regarded as more severely disabled remained largely uncatered for within the educational system. Special schools for children with learning difficulties were provided on a residential and a day basis within both cities. The balance of residential versus
day schools was different in the two cities, with just one school in Saratov and six out of eight schools in Samara being primarily residential. Most of these residential schools also had day pupils. Both cities are administrative centers for large provinces, and all special schools elsewhere in the provinces were also residential.

3. One center opened in Samara in the early 1990s was a less recent development and effectively a pioneer in this area. It was associated with one of the case study organizations, the Samara Association for Disabled Children. The three other centers mentioned had been founded relatively recently prior to the study in 1996; one of them had not yet officially opened, although it was operational.

4. This was a project supported by the Soros Foundation, which involved an integrated kindergarten for children with a specific type of learning difficulty regarded as mild and curable through training (ZPR: zaderzhka psikhicheskogo razvitia or developmental delay) together with nondonisabled children. This project does not form part of the body of analysis in this chapter, primarily because I have favored a focus on “indigenous” organizations as opposed to Western-funded projects.

5. This is a point recognized by other cross-national researchers with a commitment to the local model of disability. For example, reflecting on research in China, Stone (1997) points to the difficulty of striking a balance between the “oppression” of colluding with or condoning practices regarded by social model theorists as unjust, and the “oppression” of dismissing local research participants’ genuine concerns.

References


Interviews

Anonymous organization. 1998. Author interview. Samara, October.

Association for Disabled Children. 1998. Author interview. Samara, November.

Central Social Service Center. 1998. Author interview. Saratov, April.

Children’s Fund. 1998a. Author interview. Saratov, April.

Children’s Fund. 1998b. Author interview. Samara, October.
