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# Life conditions for families, children and young people with disabilities

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## Abstract

The aim of this article is to analyse life conditions for families with children and young people with disabilities. Special focus is on: legislation, management and organisations, social support and service, housing, education, work and daily activities and leisure activities. The method used is a case study including interviews with parents and professionals. The study also includes an analysis of documents and regulations. The study shows that the support system is transparent and accessible. At the same time managers in the municipalities' social care services interpret their responsibility in different ways thus affecting the support and service for the families. Even though the families have legal rights to a wide range of support and service, the parents have to work to gain access to these and for user influence to be exerted.

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## Introduction

Becoming and being a parent changes your life situation. The common expectations are to get a 'healthy' child that will grow, learn how to talk and walk, go to school, get an education, a job, move away from home and maybe become a parent themselves. Having a child born with a disability or receiving a disability at an early age affects one's life conditions in different ways (Lindblad, 2006). In an ongoing international study we have carried out interviews with parents, professionals and educators with the aim of comparing the situation for families with children and young people with disabilities in the Czech Republic and in Sweden. We found that legislation, organisational, cultural and socio-economic factors are important. In this article we have chosen to present some of the findings from the Swedish part of this international study.

The aim of this article is to give a description of, and discuss life conditions for, families with children and young people with disabilities. Special focus is put on: legislation, management and organisations, social support and service, education and leisure activities and in what way these factors meet the needs and rights of the families. The questions discussed are: How has the disability policy concerning life conditions for families with children and young people with disabilities developed? What are the latest current best practices? Who

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This information is correct at the time of printing but there are legislative changes on the way which will result in policy changes.

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are the families using the social support and services? What kind of social services are available and how are they provided, organised and managed? How do managers in social care describe the challenges and realities of their position? How do families with children and young people with disabilities experience the support and service from a client/user perspective?

The result is based on a study of 10 interviews with families and managers together with a document analysis. The documents included legal texts, national guidelines, local disability policy documents, minutes from the local authority meetings concerning disability issues, magazines from the user organisation and also some local newspapers. A brief case example from the interviews completes the article.

## **History of disability policy and reforms**

During the last five decades there have been great changes in the policy towards children and young people with disabilities in Sweden. The manner in which children and young people with disabilities have been catered for in the past, has reflected the dominant theoretical perspective of the period. In the 1950s and 1960s Sweden developed residential homes for young people with different kinds of disabilities, mostly for those with intellectual disabilities and severe physical disabilities. For children and young people with severe physical disabilities there were also boarding schools. As time moved on more and more of the residential homes were closed down and children with disabilities often grew up with their families instead. An exception was children with intellectual disabilities, many of whom still lived at the institutions in the 1970s.

At the end of the 1960s a developmental model was introduced and concepts of normalisation and integration were presented. The concepts are often used to describe the background to changes in legislation 'from needs to rights'. After the 1970s the social model was introduced, residential homes were replaced by group homes and support and services to the families. This even made it possible for children with severe disabilities to live together with their families. Support systems for leisure time were organised in different ways; group solutions were replaced by more individual support for leisure activities (Blomberg, 2006).

Three international agreements and policies are central in all development work in improving the situation for children with disabilities: firstly the UN Convention on the Rights of the Child (1989), secondly the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993) with a declaration of full participation in society and equality in life conditions for persons with disabilities as the main goals, and thirdly the Salamanca Declaration on Principles, Policy and Practice in Special Needs Education (UNESCO, 1994). A new Discrimination Act (Swedish Code of Statutes 2003:307) was passed in 2003 that entailed stronger support for the move to counteract discrimination due to ethnicity, religion, sexual preferences or disability. In May 2008 the UN Convention on the Rights of Persons with Disabilities entered into force and Sweden has ratified the Convention. In January 2009 the Discrimination Act was changed and new groups were added. The purpose of the new Discrimination Act 2008 (Swedish Code of Statutes 2008:567) is 'to combat discrimination and in other ways promote equal rights and opportunities regardless of sex, transgender identity or expression, ethnicity, religion or other belief, disability, sexual orientation or age'. At the

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same time a new agency, the Equality Ombudsman, was established. The agency's aim is to supervise compliance with the Act (The Government Office, 2009).

The overall strategy for children with disabilities is that the rights of the child should be respected in the same way as all other children's rights. All citizens in Sweden have the basic rights to receive service and support in accordance with the Social Services Act 2001 (Swedish Code of Statutes 2001:453), the Health Care Act 1982 (Swedish Code of Statutes 1982:763) and the Assistance Compensation Act 1993 (Swedish Code of Statutes 1993:389). In 1993, The Disability Act known as LSS in Sweden (Swedish Code of Statutes 1993:387) was passed, and local authorities took over the responsibility for the support and service provision for *all* persons with severe disabilities. The law is based on the United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities (1993). The main principle behind this law was that people with disabilities have the right to live their lives as any other citizen in society and should actively demand their rights (Lewin, 1998). The Disability Act 1993 provides rights such as advice and personal support, personal assistance, escort service, contact persons, relief services in the home, short-time minding of schoolchildren over 12-years old, short-term care, special housing for adults and daily activity. All support and service in accordance with the Disability Act 1993 is free of charge.

## **Government agencies**

The concepts of social inclusion and social exclusion are now often used in the disability field and the hallmarks are full participation in society and equality in living conditions for people with disabilities. Important measures that emphasise legal rights for persons with a disability in Sweden are: the Disability Ombudsman, a government agency (1994), the National Action Plan of Disability Policy (1999/2000) and the official report about Attitudes to Persons with Disabilities (SOU 1999:21). In spite of legislation, guidelines and recommendations, many investigations and reports have shown that people with disabilities have a low level of participation in society, lower income and difficulties in accessing higher education (The Disability Ombudsman, 2005). There are, however, many examples of the disability policy leading to positive experiences of participation and great changes in life conditions for people with disabilities (Blomberg, 2006; Wolmesjö & Blomberg, 2005). The aim of the Disability Policy is that full participation and equality for all should be reached by 2010 (SOU 1999/2000:79).

## **Population served and demographics**

The number of children with disabilities is estimated at around 140 million worldwide. Around 85% of these children live in developing countries and the proportion of children with disabilities is lower in poor countries, since many die at an early age (The Ministry for Foreign Affairs, 2001).

Sweden has a population of approximately 9.3 million people (49.6% male and 50.4% female). Two million of these are children under the age of 18 (Statistiska centralbyran (SCB) 2006). In the municipality where our case study was carried out, Växjö, there are approximately 80,000 inhabitants with an equal number of men and women (SCB, 2005). Ten percent (approx.) have some form of disability. Twenty-nine percent (approx.) of all services provided in accordance with the Disability Act 1993 in the municipality are for children and

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young people aged 22 or younger. In Sweden about 200 children and young people with disabilities reside in family homes and just over 1,000 reside in special housing for children and young people (National Board of Health and Welfare, 2006).

## **Agencies and authorities responsible for policies and practices**

The provision of services in Swedish society is characterised by a division of responsibility with a strong influence exerted by government agencies on the one hand together with decentralised decision making and rights to carry out services at the local county and municipal levels on the other. The responsibility for providing support and services for persons with disabilities is divided between three societal levels: governmental, regional/ county council level and local/ municipal level.

The state is responsible for legislation, social insurance and general planning. Government decisions are not binding and local authorities and county councils enjoy a great deal of freedom to decide on the quality and nature of the practical measures undertaken. The National Board of Health and Welfare and the National Agency of Education produce statistics every year on persons receiving special services (National Board of Health and Welfare, 2005; The Swedish National Agency of Education, 2005). The various services are organised and provided by both the county councils and the municipalities. Most of the service providers are from the public sector but there are also some from the private sector.

The county councils have the responsibility for health care. All children are offered free health care and the Child Health Service (CHS) provides an immunisation programme, surveillance and general medical care. Habilitation and rehabilitation are tasks incumbent on the county councils, as is the provision of technical aids and interpreting services. In the county council multi-professional teams consisting of social workers, psychologists, occupational therapists, physiotherapists and special teachers work in the habilitation and rehabilitation organisations. The aim of the child habilitation teams is to enhance the development of the child by building on his/her resources and giving the child optimal possibilities for an independent life. The habilitation team works together with the child or young person with a disability, seeking to utilise the child's resources in every day life, providing tools for independent living, and offering the rights for support and service. The aims of the habilitation plan are: participation with user influence, development of cooperation with other organisations, and evaluation of support and services. The child habilitation team works both on an individual level and also a group and societal level. One specialised activity is the 'Datatek' – Computer lab, which offers support to children and young people in using computers in a special training programme, as well as pleasure and leisure.

The municipalities are responsible for planning housing and ensuring that everyone should have a home in accordance with their needs (Swedish Institute, 2005). Appointees and trustees with various powers of attorney can also be of assistance to families with children and young people with disabilities where support is needed. Another important provider is the Social Insurance Office that pays out sickness benefits, allowances for families and pensions.

The municipalities also have responsibility for education, daily activities and leisure activities. Within the education field, pre-school activities are provided for children from the age of one and until they start school at the age of six or seven. Municipalities must

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provide pre-school activities free of charge for all children whose parents work or study and for children with particular needs for pre-school. The Education Act 1985 (Swedish Code of Statutes, 1985:1101) states that all children shall have equal access to education and have the right to attend a comprehensive basic school for nine years from the age of six or seven-years old. Remedial teachers are employed in the schools and in accordance with legislation children with disabilities in need of special support and service also have the right to have a personal assistant in school. The same assistant can follow the child from year one until year nine if necessary. The main focus for the assistant is to support the child in his/her daily activities and social participation. To support the education process there are special teachers. The basic principle is a responsibility to make the school and education accessible for all students (buildings, technical aids, etc.).

After the nine-year compulsory school there is a right to take part in upper secondary school for three or four years. The national guidelines are specific about every child's right to be treated on the basis of his/her own abilities and about society's obligation to organise the activity in a good way (Ds, 2001:19). Special support shall also be given to pupils who have difficulties with their schoolwork. For young people who do not meet the requirements of regular upper secondary school, such as those children and young people with intellectual disabilities, the municipality has an obligation to offer these children a place in an upper secondary school programme for pupils with intellectual disabilities. Since 2006, there has been a law against discrimination of children and young people in school (Swedish Code of Statutes, 2006:67). As is the case for the regular upper secondary school, upper secondary education for pupils with intellectual disabilities has a national, specially designed individual four-year programme. There are some special schools for children who are deaf or have hearing deficiencies. There are four state resource centres for special needs education catering for children who are visually impaired, who have hearing deficiencies or are deaf, who have intellectual disabilities and who have mobility impairments.

A government commission investigated the situation for children/pupils with disabilities in Swedish schools (SOU 1998:66). Conclusions from this report were that it was important to stop thinking about pupils with disabilities as a special group within school since the aim of the school system was to see every pupil with a disability as an individual. The most effective way for the government to exert influence in a decentralised school system was to ensure that the teachers had appropriate qualifications. The government thus decided to introduce a new education programme for teachers which started during 2001 and which highlighted this perspective for children and young people with disability (SOU 1999.63, Prop.1999/2000:135).

## **The study of life conditions**

Results from our study show that leisure activities are organised and provided by the disability associations, habilitation teams, churches and other voluntary organisations. The interviewed families spoke about the difficulties in finding vacation opportunities for their children during the summer: 'It's difficult to find leisure activities and summer camps that are accessible and can offer all the assistance that he needs'. The families have experiences of meeting many different experts, and often have the role of coordinating service and support. The families also experience having to 'fight' to get their statutory rights for support and service.

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In her dissertation, Lindblad (2006) analysed the lived experiences of parents of children with disabilities and she looked at the support offered and the qualifications of professionals. The results from Lindblad's study (2006) indicate the difference between formal and informal support. The formal support gives the parents trust and possibilities to give their child a good life when the professionals work with compassion to find unique solutions for every child. The relationship to other children in school makes it possible for them to have a good childhood. The informal support, as relationships with other persons like grandparents, siblings, friends and neighbours gives love, understanding, flexibility, relief, natural togetherness and care (Lindblad, 2006).

The families in our study also reflect on the situation for the brothers and sisters of children with a disability. The siblings have to grow up quickly and take greater responsibility for their own lives. They, as well as the parents, need information and knowledge about the disability and treatment. The children and youth habilitation team offers special support groups for siblings where they can meet other young people in the same situation. The families are in a vulnerable situation and dependent on the attitude, approach and treatment of the professionals.

### **Municipal organisations and management of disability care**

In the municipality of Växjö the care of children (up to 18-years old) with or without disabilities is organised by a special board or committee focused on child care. Special assessment officers work with children and young persons with disabilities. For adults the organisation of care of persons with disabilities has been separated from that for care of the elderly. Special services for children and young people with disabilities are offered in accordance with the legislation, The Disability Act 1993 (Swedish Code of Statutes, 1993:387) and Social Service Act 2001 (Swedish Code of Statutes, 2001:453). These include counselling support, home adoption, daily activity, travel services, technical devices, contact person, short-term care, personal assistance, instructor of persons with severe visual impairments and / or home help services and health care. All children and young people with disabilities in Växjö live together with their families with support and service.

Växjö is the largest city in this county and there are three different habilitation teams working in separate districts both for children and young people. Some 550 children and young people receive support and service through these habilitation teams and approximately 400 of those are between seven and 18-years old with physical disabilities, intellectual disabilities and autism (Interviews with managers, Växjö municipality). A total of 20 managers and 920 employees are responsible for different areas of disability care (housing, home help care and personal assistance) for children, young people and adults in Växjö (Växjö municipality, 2006). The educational background of managers and staff members varies (Wolmesjö, 2005). The most common background for the position of a manager in our study is an academic degree as a social worker, occupational therapist or nurse. Qualifications for staff members are training as a nurse assistant or recreation leader for young persons or a similar qualification.

The educational background and differences in number of employees, responsibility, etc impact on the leadership and the way managers deal with different challenges (Wolmesjö, 2005; 2008). One of these challenges as a manager is to implement legislation and regulations

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and be the one 'setting the norms'. Professionals with differing qualifications and background enrich the organisation, but sometimes diverse professional values can conflict with each other. One of the interviewed managers described her situation: 'I have a large unit with many staff members with different backgrounds and qualifications that sometimes creates conflicts in the organisation'. Even though there is a relatively high level of education among staff members the implementation of the disability policies is still difficult in relation to the values and the attitudes held by assessment officers, teachers and politicians (SOU,1999:21) resulting in dilemmas that have to be handled by the social work manager (Wolmesjö, 2008).

In order to ensure that the disability care organisation respects user participation, the managers we interviewed are required to work with a balance score card as a method to measure the quality of their work in four different areas. Goals are to be set for:

- 1) those who receive the care and services;
- 2) those that provide the care and services;
- 3) the economy and
- 4) the organisation's in-house training.

According to the Social Service Act 2001 (Swedish Code of Statutes, 2001:453), what's best for the child has to be put in focus and if possible the child should have an active role in decision making about their life situation.

As a manager for the personal assistants who provide support and service to children, young people or adults with severe disabilities, the major task is to 'support staff members so that they can give their best to the person with a disability and stay focused on him/her and his/her needs' (Interviews with managers, Växjö municipality). A large responsibility is delegated to each team of staff members. The team is responsible for a part of the economy, planning the schedule, calling in staff and planning the daily activities of the person they work with and then reporting back to the manager. The manager's role is thus mainly that of a coordinator, although dealing with different kinds of conflicts is also part of this role. It can entail conflicts between different staff members, between relatives and staff or conflicts between the user and a staff member. 'It is better if the conflict is with me than between the user and the employee. Then it won't be a burden on their relationship... I often act as a buffer, in this role' (Interviews with managers, Växjö municipality). The number of employees per manager has increased in recent years. This has brought new challenges and changed management from being close to the user with personal knowledge of the child or young person towards management at a distance where managers have become more professional as managers and leadership is 'transferred' to someone else in the organisation. One issue that has been discussed is the need for new competence among employees, which has also been highlighted by the National Board of Health and Welfare (2004).

## **Client issues**

The user organisations in the disability field in the county of Kronoberg are organised in a special resource centre, the Disability Movement Resource Centre. The centre started as a project in 1995 and is now permanently established and staffed by eight people, most of them with disabilities. They are financed mainly by the county council and the eight municipalities in the county as well as receiving income from assignments. They cooperate with the local user organisations, providing support and services, and cooperate with Växjö University in

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education and special projects. Special tasks for the organisation are issues about accessibility, user influence, treatment and equal rights. School networks and support groups are examples of activities aimed at children and their families. The most important work at the centre is to focus on accessibility in society for people with disabilities, on networking and on lecturing in schools for young pupils as well as for students and employees in different organisations.

From the interviews with user participants several persons stressed that difficulties are linked to experiences of a feeling that you as a person with a disability 'should be happy and content and not demanding too much'. One of the young adult informants continues:

...but I can not sit here in my wheel-chair and be thankful for the support, I have a legal right to it. A lot of the support is dependent on my own ability to apply and argue for it, my own knowledge about support and service, laws etc. It is easy for the authorities to say no to people who are not able to argue for their rights. I am capable of reading the official documents and can reason with the authorities using good arguments.

Parents and young persons point out that: 'It can be difficult if your situation doesn't fit into the mainstream design of the law' (young female, Czech Republic). Furthermore there is a request from the user organisations for continual investigations, evaluations and analyses of the consequences of the Disability Act 1993 (Swedish Code of Statutes 1993:387; 2009:567). 'The Disability Act with services and support has been implemented quickly and the services are well used' (mother of young girl, Sweden).

## **A case example**

Below is an excerpt from an interview with a mother of a seven-year old child with a rare intellectual disability and autism. The text includes examples of service and support that are offered, but also of a lack of knowledge about what parents need, the importance of the behaviour of professionals, and the lack of information etc.

One of the first experiences described by this mother is related to the negative impression they got of the professionals they met as parents when they first realised their daughter had a disability and special needs. 'Even though several years have passed the persons you meet and what they say, and how they behave remains in your memory a long time after.' The first professional contact with the child habilitation centre was when their daughter was one-year old. After a few years, during pre-school they came in contact with the Petö method and described the following experiences:

It was something totally different from the training she gets at school. I understood that the county council did not accept the educational method they used at my daughter's school. It is a special Hungarian method, developed for children with cerebral palsy, the Petö method. It is very intensive and can be experienced as difficult, but some children need it and it works well for my daughter.

A parent we interviewed describes a dilemma that has also been described by other parents in our study. When new methods are available and sometimes controversial the parents have to be strong and 'fight' if they want something other than that which is offered by the habilitation centre. Our interviewed parents point out that it is hard being seen as the 'expert' knowing what is 'best' for their child.



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The feeling of being excluded from 'ordinary' family activities that 'ordinary' families take part in has been brought up during the interviews, but even among parent groups where all the children have disabilities there can be a feeling of exclusion:

Even though our children did not have the same kind of disability and I, for a long time felt that the other children developed much faster than my daughter did... I felt that I belonged (to the parents group), while at the same time I felt excluded. Still it means a lot to me to get the opportunity to talk and get the possibility to describe these feelings that I have and just to get away from home means a lot.

Replying to a direct question about what is missing or needs to be developed in social care for children with disabilities from a parent's perspective, the mother of a seven-year old girl answered: 'Yes, it has to do with information about what legal rights and possibilities are available. You (as a parent) have to find out a lot by yourself'.

From a professional perspective this can be seen as a dilemma. There are many professionals involved in treatment, caregiving, etc., when one has a child with special needs. Who should be the one responsible to make sure that all information has been given? Our experiences from the international study (Wolmesjö & Blomberg, 2005) are that disability organisations are doing a good job in this field.

Other situations described by the parents that have made impressions and affected the way they have felt as a parent, are various meetings with professionals and how they behave towards one's child (as also mentioned above). Some persons act in a professional manner; they listen to the individual and try hard to understand the needs of the child, even if the child has severe difficulties in expressing him/herself. On the other hand when professionals approach one's child as though he/she is an object, ignoring him/her and not 'seeing' the child, the latter is then described by the professionals as being: 'extremely difficult and a problem'. The mother's comment on this was:

To work with people is probably the most important job there is, and I have seen some assistants come and go...they are very important people. You should take care of and appreciate to work with people. Not everyone is capable of doing that kind of work.

Our parents in this interview study described the need for information about what support and services are available for them or their child, how to express oneself in an application and how to complain. 'You should not have to be a legal scientist or a lawyer to understand and learn how to find information.'

Another issue discussed by our parents is the role of being a parent to a child with a disability in comparison with having a child that does not have special needs. 'In ordinary circumstances the children will grow up and become independent, but in my daughter's case, she will always be dependent on us.' Most of the interviewed parents stated that it was difficult to think about the future and how their life situation would look like for them and their child five or 10 years from now. 'Now, the most important is to try to make the best of the situation, to try to live!'

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## Current challenges

It has been established that families with children and young people with disabilities find themselves in a borderland between the social services, the school system and the health care system (Lewin, 1998). They encounter difficulties in their life which gives them the right to receive assistance from society. The support and service system has changed the approach from needs to rights and from patient to citizen. How the needs and rights of children and young people with disabilities are met depends on current education and social policy. Citizenship is a relationship between the state and the individuals and the organisation of schools, services and support reflects this relationship (Gynnerstedt & Blomberg, 2004). Full participation in society and equality in life conditions and an inclusive school are central goals for disability policy. The political aims and implementation of the law influence the lives of families with children and young people with disabilities.

The families in our study felt they had security through their legal rights and the high level of public information. However, they also experienced a gap between what is stated in the policies and what they in reality receive in support. The gap can be seen in terms of user influence in relation to the influence of the 'experts'. Another conclusion from our study is that management of social care has changed from management being 'close to the user' to management being 'at a distance'. The managers of today saw themselves as being more professional in their administrative roles rather than in the practical care situations and they thus delegated responsibility to their employees or professional teams. Their biggest task has become that of being the strategic leader and ensuring that their organisation attains the goals stated in the legislation and in the disability policies that have been influenced by the change from a medical model to a social model.

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