

# Becoming a client of the Danish social service system increases stress in parents of disabled infants

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## ABSTRACT

**INTRODUCTION:** Parents of a young child with severe disabilities are facing a large range of new challenges; furthermore, most of these families have extended social needs regarding information, financial support, day care facilities, disability aids, etc. Many parents with disabled children have been found to be dissatisfied with social services. This study explores parents' experiences with Danish social services during their transition to a new daily life after the birth of a severely disabled child.

**METHODS:** Repeated qualitative interviews were performed individually with 16 parents of a severely disabled young child during the first two years after the diagnosis of the child's disabilities. Data were analysed using grounded theory.

**RESULTS:** We found that the encounter with the social services increased stress in the families. Parental expectations were not met, especially regarding information; parents felt alienated, and obtaining social support was very resource consuming. Parents' needs regarding practical support and empathic case-working were not met and they spent much time and effort due to lacking continuity between sectors.

**CONCLUSION:** Parents have specific needs when becoming clients in the social service system whose organisation of social services needs improvement. Health care professionals are advised to identify problems and support cooperation between the parents and the social service system, as well as to report the health-related consequences of prolonged and inefficient case-working for the child and its parents.

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The process of being discharged after prolonged hospitalization with a newly-diagnosed, severely disabled infant is stressful and challenging for most parents [1, 2]. The parents' encounter with the social service system is an additional challenge parents are facing in this context. Parents of a severely disabled child are often dependent on assistance from the social service system for information, financial support, day care facilities, disability aids, etc.

Parents have to cope with this new situation concurrently with many other ongoing practical and emotional stressors: medical complications, financial consequences, career changes, siblings' reactions, spousal relationship and worries about the future. The interaction between the parents and the health care system is often difficult and unsatisfactory, especially regarding information and communication [3, 4]. The purposes and interventions of the healthcare system are very different from those of the social system. Only the latter are discussed in this article. Several studies have found many parents to be dissatisfied with the social services [2, 5-7], especially families with a severely impaired child [3, 8]. Several causes of parental dissatisfaction are related to the organization of the social service system, e.g. the existence of many different service providers, insufficient information, bureaucratic procedures and a lack of coordination [6, 9]. The social workers' attitudes towards the families are also perceived as a stressor [10]. In Denmark, expenditure on social services for families with disabled children doubled in fixed value during the 1990s, and, yet, a rather high degree of parental dissatisfaction was found [11].

In previous studies, the encounter between parents and the social service system was examined in retrospective designs in which the interaction between parents and the social service system had existed over a number of years [8, 12, 13]. The purpose of the present study was to explore parents' experiences with social services during the transition to a new daily life after the birth of a severely disabled child.

## METHODS

### The Danish setting

All Danish citizens are entitled to social services according to their needs. Responsibility for the public health service lies in the five Danish regions. The 98 smaller municipalities are responsible for the majority of social services, such as day care, disability aids, physiotherapy, special institutions, etc. Most social services related to children with disabilities are provided by the public service system. Private programs and support are rarely used in Denmark, and all support is either free or related to the household income. The social worker is the key worker and has the dual obligation of informing and co-

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operating with parents and deciding, often in a team of case-workers, on what and how much support the family is entitled to receive.

### Design

We conducted the study using semi-structured individual interviews. The study was conducted in Denmark from 2003 to 2005 as part of an explorative study on parental reactions, coping and resources.

Purposeful sampling was used to ensure diversity in experiences. Both parents were interviewed twice during the first two years after disclosure of the disabling condition. Data were analysed using the method of grounded theory [14].

Trial registration: not relevant.

### Data sampling

The participants were recruited in co-operation with the neuro-paediatric department and the neonatal ward at the State University Hospital of Copenhagen (Rigshospitalet) in Denmark after approval from the local research ethics committee.

All parents of 11 children suspected to be severely disabled were invited to participate. Eight sets of parents of children diagnosed with inborn severe mental

and physical disabilities consented to participate. The children's mean age was four months (1-27 months) at the time of inclusion (Table 1).

### Data collection

The first author (AHG) conducted semi-structured interviews separately with each parent. The first interviews were conducted at a mean age of three months (1-9 months) after disclosure of the disabilities. See Table 2 for the contents of the interview guides. All 32 interviews were audio taped and transcribed verbatim.

### Analysis

AHG conducted a grounded theory analysis. Main themes pervading all interviews are listed in Table 3. The theme of the *encounter with the social service system* proved to be of central and paramount importance to all parents. It was therefore chosen for further analysis, but during the analysis it was constantly related to the context listed in Table 3.

Some of the interviews were co-coded and discussed with the second author to strengthen the study's validity. A theoretical framework of stress and coping was used during the analysis in this study, as this proved appropriate in order to interpret the findings. The concept of stress was defined according to Lazarus [15]:



TABLE 1

Characteristics of the interview families. F = female; M = male.

Sex of child	Age at first interview	Siblings	Diagnosis	Symptoms	Parental education	Social services at first interview	Social services at second interview
Male	2 months	First child	Unknown	Severely impaired interaction and developmental delay, hypotonia, epileptic seizures. Normal feeding. Died 22 months old	Both parents higher education	None	Specialised day-care Disability aids, such as a special bicycle and corset
Male	4 months	First child	Unknown	Impaired interaction, tube feeding, > 100 seizures daily, dystonia	F = higher education student M = further education	None	Home support 18 hours a day, salary compensation for the mother to care for the child at home, several disability aids. Physiotherapist home visiting twice a week
Male	8 months	First child	Infantile spasms	Delayed motor and mental development, hypotonia	F = further education M = higher education	Support at home a few hours every day to assist in exercise for the child. Several disability aids at home	Specialised day-care, support at home a few hours a week. Mother received salary compensation. Several disability aids at home
Male	10 months	First child	Unknown	Delayed motor- and mental development, normal feeding	F = vocational training M = vocational training and higher education student	Awaiting training aids from the municipality	Daily support at home, mother received salary compensation, many disability aids at home
Female	1 month	First child	Lissencephalia	Breast feeding in the neonatal period, then tube-feeding, developed severe dystonia, died 10 months old	Both parents higher education	None	Home support a few hours daily, shortly before the death of the child
Male	8 months	First child	Lumbar meningomyelocele	Cerebral shunt	F = higher education student M = higher education	Leg braces	Child in normal kindergarten with personal assistant Aids at home, leg braces

“Psychological stress is a particular relationship between the person and the environment that is appraised by the person as taxing or exceeding his or her resources and endangering his or her well-being”.

## RESULTS

The main finding was that the encounter with the social service system during the transition to a new daily life contributed to increase stress in parents with a severely disabled child. The encounter with the social service system took place when the parents were in the midst of a very complex and challenging life situation. The parents had much need for extensive and timely support from the social service system, but it was exhausting for them to obtain such support as is detailed in the themes below:

### Lack of continuity between sectors

Contact with the social services and proper organisation of support and disability aids for the family had not been planned before their discharge from hospital. The family often needed immediate information and daily support after discharge. Consequently, the parents had to make contact with many different professionals while struggling with daily life at home. Often they did not know who to contact or what kind of support was available.

### Applying for social services

First of all, parents needed information in order to understand what kind of support they were entitled to receive; they had to define their needs and options themselves; even relatively basic information was not provided.

### Structure of the social service system

The structure of the social service system was in itself a cause of much stress and frustration. First of all, considerable time and resources were used in navigating the system. Support was experienced by the parents as being predefined by law and custom rather than being related to the families' actual needs. In several cases, parents gave up applying for something they needed and were entitled to because of the extreme demands on their time and resources.

### Independent experts were needed

All the parents felt that they lacked necessary information, which might otherwise have led them to apply for services. Most parents had turned to external or ad hoc advice and information from independent parents' groups, social organisations, social worker friends, or the internet. Several of the families experienced that their needs were only met when they obtained external help to find information and write applications.



TABLE 2

Main interview themes.

Parents' perception of the diagnostic process and disclosure
Parents' ways of managing practical and emotional demands
Parents' interaction with the health-care and social service systems
Life changes during the study period
Parents' perception of their child and the disability
Parents' ways of mobilizing resources
Parents' existential belief systems

### The social worker

In only one case did parents describe the interaction with the social worker as cooperation. In all other cases, the social worker was perceived as a counterpart in a negotiation about money. An empathic, insightful approach from the social worker was rarely reported.

### Expectations of the social service system

None of the parents in our study had ever had contact with the social service system before. They experienced a troubling incongruence between their former beliefs and expectations of the welfare system and their actual experiences when they needed support.

Parents did not expect the system to solve all their problems, but they expected advice, information, empathy and cooperation, and their experience was that



TABLE 3

Main analytic themes

Themes emerging from analysis of all interviews	Properties
Health status and care for the child	Abilities, feeding, seizures, infections, medications, training, stimulation, day-care, respite, night-time sleep, difficulties with lifting, signs of normality
Transition to a new daily life	Normal consequences of being a family, aiming at normalisation, becoming an unusual family, physical consequences of lifting, changes in social relations, siblings' reactions and well-being, financial/work-related consequences
Encounters with the social service system	Expectations, negotiations, clientization, information, case worker, offers/needs, money/needs, unmet needs, empathy, continuity, coordination, plans, bureaucracy, consequences, conflicts, wishes and needs
Cooperation with the health-care system	Information, health professionals personal skills, conflicts, medication, training, treatment level, responsibility, quality of life, + diagnosis, coordination, continuity, plans, wishes and needs
Relation to child	Emotions, contact, stimulation, ambitions, joy and sorrow, relationship with siblings
Marital life	Differences, disagreements, responsibilities, strengths, cooperation
Future	What to expect? Dreams, fears, hopes, getting more children, who will take over when we get old, can we keep coping?
Practical coping	Treatment/training, achieving new skills, taking control, information seeking
Emotional coping	Social support, other parents, changing goals, reappraisals of the experience, existential beliefs and priorities, wishful thinking, making sense of circumstances, resource creation

this was not provided. As a result, they experienced a lack of control over their own lives, a sense of being left alone, and they felt disappointed in their expectations (Table 4).

## DISCUSSION

We found that the encounter with the social service system did not support the parents' efforts and struggles in creating a new family life. During the period of the parents' lives covered by this study, the parents were under much stress [2, 4]. The definition of stress implies that stress is a personal relationship between a person and his or her environment and that this relationship may change over time. Experiences of lacking control and uncertainty about the future are well-known contributors to feelings of severe stress, as well as unplanned changes in personal conditions, plans and identity. As all these experiences were a consistent part of the parents' interaction with the social service system, they were regarded as factors contributing to increase stress during this period of the parents' lives. Similar findings have been reported from other social service settings [2]. Furthermore, we found that parents lacked structured support and timely information in their new life situation, and that their dissatisfaction was not primarily related to the amount of funding received. Another Danish study reported similar findings. It concluded that the general dissatisfaction should not be seen as resulting from exorbitant demands from a group of consumers of social services, but rather as related to circumstances

that could be improved without a notable increase in costs [5]. Likewise, it was concluded in a report from the Swedish Ministry of Health and Social Affairs that the quality of service depends on the meeting between the family and the social worker [16]. Several studies have reported that satisfaction with the provision of care or service is a powerful indicator of the quality of care or service offered at the organisational level as well as at the individual level [17]. In Denmark, the social worker is the key worker in social service delivery and in the co-operation between health services and the social services. Our results indicate that the duality of the social worker's function undermined the intentions of the social service system: i.e. to ensure that the disabled child had the same possibilities for personal development, health and self-realisation as other children. The ability to "fight" and be very persistent in relation to the social service system may also be unevenly distributed among families, thus causing social inequality in support. This has been found in several other studies [1]. Additionally, a large body of research has found that caring for a disabled child places the family under significant financial strain.

Some frustrations and distress may have been caused by the fact that parents were struggling to come to terms with their new life situation – but many positive feelings and consequences have also been reported [18-20]. Green [20] found that the burden of caring for a disabled child is a matter of socio-structural constraints rather than emotional distress: as one parent was cited, »we're tired, not sad«. This indicates that parents are not »demanding and in crisis«, but are facing so many stressors at the same time that the bearable threshold is likely to be reached at some point. The support system should act according to this situation.

## Methodological considerations

There was only a small degree of recall bias as parents were interviewed in the midst of their specific experiences. In all cases, every parent was interviewed individually, so experiences could be validated from two perspectives. Furthermore, the results were validated with the participants. Only parents of severely disabled children with multiple problems and needs were included. We do not know whether our results are applicable to families of children with less complex needs or whether experiences change over time. Furthermore, only five of the Danish municipalities were represented; substantial local differences are likely as services are organised differently across municipalities.

## Clinical implications

The health care system and health professionals are closely involved with the families of disabled children;

TABLE 4

Theme and Citation.

Theme	Citation
Lack of continuity between sectors	<i>"It was a relief to leave the hospital, but then we just sat there, all alone, and were about to totally break down, we never slept. And the big problem was that no one took care of us. There is nobody in the public service system who takes care of you"</i> (Frida 1:354)
Applying for social services	<i>"... and then you feel all alone, all the way through the process. Both related to the doctors and the social service system. Nobody told me at any time that we could get some help..."</i> (Helle 1:699)
Structure of the social service system	<i>"Support possibilities? According to legislation they are really good; the conditions are surely there, but not in reality. I really think it has been a farce when our social worker says we can get help for this and that, but it costs us just as much in working hours to write all these applications"</i> (Dorte 2:666)
Needing independent experts:	<i>"The greatest help we got was from a local, independent organization, because their social worker, she was definitely on the parents' side"</i> (Anders 2:545)
The social worker	<i>"She listens a lot more, the case worker we have got now, but it is like they need this documentation, because otherwise...nothing happens, they need the documents to be in order, to find it okay to allocate support"</i> (Beate 2:199)
Expectations of the social service system	<i>"Well... before we came in contact with the health care system and the social service system, I thought that it worked. I happily paid my taxes because I knew it was for a good purpose..."</i> (Bo 2:662) <i>"When you are in a community system, you become very small. Suddenly you don't have any influence over your own life"</i> (Beate 2:1372)

they are responsible for the child's treatment, but may also identify and address problems in the interaction between parents and the social service system. Furthermore, health-related consequences of insufficient information, delayed case work and unmet needs in the child and the family must be reported to the social service authorities.

### Implications for social services

Our findings are consistent with both other Danish studies and international findings and a significant change in the organisation of social services is therefore recommended. Two specific areas need re-organisation: an independent cross-sectional key-worker should be assigned to each family, and a real implementation of the three central aspects of Family-Centered Service: information exchange, respectful and supportive care and enabling partnership between parents and service providers [17]. None of these suggestions should cause any significant increase in social costs.

### CONCLUSION

Parents of a child with newly diagnosed severe disabilities have special needs during the period of transition from hospitalisation to a new life at home. Cooperation with the social service system in this period is severely disappointing to the parents and adds considerable stress to their daily life.

Significant improvements in social support could be made by providing information and making plans for the future together with the parents at the time of discharge in a cooperation between the sectors.

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