Influence of macrostructure of society on the life situation of families with a child with intellectual disability: Sweden as an example

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Abstract

Background Most studies on families with children with intellectual disability (ID) have been carried out in the UK or the USA, and are influenced by the societal organization, and political and economic climate of those countries. In the USA and the UK, the care and well-being of children, with or without ID, are seen almost exclusively as the individual family’s responsibility. In Sweden, the care and well-being of children are seen more as a joint responsibility. Swedish society has developed many privileges for all parents in order to help them care for their children, and the support for parents of children with disabilities is provided exclusively by the Government and the community. The overall question explored in this descriptive, quantitative and qualitative study was: Are families in Sweden experiencing the stressors and life situations described in the studies of parents in more individualistic societies?

Methods Two hundred and twenty-six families with children with ID and 234 control families with children ranging from 0 to 16 years of age answered mail surveys.

Results Taken together, parents in Sweden describe most of the stressors proposed in the international literature with the exception of financial strain. Restricted social life and time restrictions seem to be the two most evident and bothersome stressors for Swedish families with children who have ID.

Conclusions As in previous research, the parents of children with ID and autism experienced more stressors and restrictions in their lives than the parents of children with DS and control families.

Keywords life situation, macrostructure, society, Sweden

Introduction

In a review of the recent literature on family stress and burden in the families of children with intellectual disability (ID), Blacher & Hatton (2001) concluded that ‘the impact of disability on the family is clearly reflective of the political and economic climate, and as these change, so too will the level of burden’ (p. 480). Most of the studies on families with children with ID have been carried out in the UK or the USA, and are influenced by the societal organization, and political and economic climate of those countries. In both the UK and the USA, the care and well-being of children, with or without ID, are seen
almost exclusively as the individual family’s responsibility (Scarr 1996; Kamerman 2000; Shearn & Todd 2000). In Sweden, on the other hand, the care and well-being of children are seen more as a joint responsibility (Myrdal 1947; Hwang & Broberg 1992; Scarr 1996; Kamerman 2000).

Through social engineering during the last century, Swedish society developed many privileges for all parents in order to help them care for their children, for example: a monthly child allowance of approximately US$95 per child; free maternity care and parental education; free well-baby clinics; 390 days of paid parental leave (and another 90 days with minimal pay); highly subsidized day-care to all children; the right for all parents of preschool children to work part time (with reduced pay); the right to stay home from work to take care of ill children for 120 days per year, with pay; and highly subsidized health and medical care for all citizens (Moen 1989; Sundström 1991; Haas 1992; Hwang & Broberg 1992; Sandqvist 1992; Haas 1993; Gatmon 1999). In addition to these privileges available to all parents in Sweden, families of children with ID are by law (LSS 1994) entitled to seek ‘support and services to people with disabilities’ from their community (Högberg 1996). The spirit of the law is that parents should be seen as the primary experts on their children’s and their family’s needs, and should be treated as collaborators and partners by professionals (Bradley & Blaney 1996; Högberg 1996).

The support and service system available to families in Sweden are almost exclusively built on resources from the Government and community, and rely to a very limited extent on private funds or insurance (Bradley & Blaney 1996). Families are referred to multidisciplinary teams from the maternity hospital or from well-baby clinics (which serve 100% of the infants and toddlers in Sweden) when delays/disabilities are discovered. From the community, parents can seek the following services, for example: free or highly subsidized transportation to school and to appointments; free necessary aids such as wheelchairs, lifts and special strollers; financial and practical assistance to modify their home or car to the needs of their child; respite care; and monthly financial assistance (for the coverage of additional costs and lost income as a result of the child’s disability, ranging from US$170 to US$760 per month). When children with disabilities grow up, different kinds of work environments and independent living arrangements are available, as well as a pension to ensure that children with disabilities do not have to be totally economically dependent on their parents.

According to Bronfenbrenner’s (1979) socio-ecological model, the macro-structure of a society affects individual’s psychological development and experiences. In what ways may the macro-structure in Sweden influence parents’ experiences of having a child with an ID? The overall question that is to be explored in the present descriptive, quantitative and qualitative study is: Are families in Sweden experiencing the stressors and life situations described in the studies of parents in other societies; for example, the US and the UK? A review by Blacher & Hatton (2001) showed that, even though the impact of a child with ID seems to influence families less negatively nowadays (Flaherty & Glidden 2000; Grant & Whitell 2000) than in previous decades, many families still experience significant stress levels (Baxter et al. 2000; Fidler et al. 2000; Hintermair 2000). The data from the present study will be structured around eight categories of potential stress to parents of children with ID (the first seven proposed by McCubbin et al. 1982):

1. **Financial hardship.** Financial difficulties are sometimes caused by the additional costs of caring for a disabled child in combination with decreased possibilities for both parents to take part in paid work (Harris & McHale 1989; Herman & Thompson 1995; Beresford 1996; Sloper 1999).
2. **Strained emotional relationships within the family** (Bristol et al. 1988; Fisman et al. 1989). Mothers who do experience support from their partner experience less stress and depression (Gowen et al. 1989; Reddon et al. 1992; Wallander & Venters 1995; Simmerman et al. 2001).
3. **Modification of family activities and goals**. Role restriction and limitations in pursuing a career are often reported by the mothers of children with ID (Reddon et al. 1992; Gallimore et al. 1993; Barnett & Boyce 1995; Herman & Thompson 1995; Wallander & Venters 1995; Knox et al. 2000; Shearn & Todd 2000).
4. **Restricted social life**. Parents of children with ID have more contact with family members and less contact with friends than parents of developmentally normal children (Kazak & Marvin 1984; Herman & Thompson 1995; Heller et al. 2000).
5 Time restrictions caused by care demands. Time restrictions and the disruption of daily life have been found to be more frequent in parents of children with ID than in control families (Barnett & Boyce 1995; Carpinello et al. 1995; Herman & Thompson 1995; Todd & Shearn 1996; Sloper 1999; Grant & Whittell 2000; Scorgie & Sobsey 2000; Shearn & Todd 2000). Many families devote more time to child care, and spend less time in social activities and enjoy less active free time (Barnett & Boyce 1995; Sanders & Morgan 1997).

6 Family contact with professionals. Having to maintain contact with several professionals, such as medical professionals, special education teachers and respite homes, is not only time consuming, but is also often associated with frustration, disappointment and anger (Beresford 1996; Sloper 1999; Knox et al. 2000).

7 Mourning and depression. Studies of different populations of parents with children with disabilities suggest that 35–53% of mothers with children with disabilities have symptoms of depression (Bristol et al. 1988; Hoare et al. 1998; Carpinello et al. 1995; Blacher et al. 1997; Veisson 1999; Olsson & Hwang 2001). The depressive reactions can be seen both as a consequence of the mourning process and of a stressful life situation.

8 Several studies investigating the impact of different diagnoses on stress levels have found that the parents of children with autism experience more stress that parents of children with ID without autism (Fisman et al. 1989; Ryde-Brandt 1990; Dumas et al. 1991; Sanders & Morgan 1997) and that families with children with multiple impairments are at high risk for unmet needs (Axtell et al. 1995). Families of children with Down’s syndrome (DS) consistently appear to cope better than families with other diagnoses (Dykens & Hodapp 2001). The heightened presence of behavioural problems in children with autism and in those with multiple impairments, compared to children with DS, probably account for much of the increase in parental stress in these families (McIntyre et al. 2002).

Subjects and methods

Measures

The present study used a mailed survey, which took approximately 45 min to fill out, included both open-ended questions and fixed alternatives, and was designed to cover a broad range of topics which can be summarized as follows: (1) family composition; (2) information on the target child; (3) contact with professionals; (4) division of household chores; (5) socio-economic status; (6) work situation and work changes; (7) time and possibilities for recreation and vacation; (8) positive aspects; and (9) spontaneous comments. The open-ended answers have been grouped and coded into categories based on similarities of answers. Since some parents did not completely answer all the questions, the number of participants differ slightly between different questions. The last page of the survey was left blank so that parents could write down comments. Sixty-six parents (30%) of children with ID wrote down spontaneous comments, some of which are cited in the present study to enrich the understanding of the families’ life-situations.

Socio-economic status was assessed using the Hollingshead Four Factor Index of Social Position (Hollingshead 1975; Broberg 1992). This is an index of the families’ socio-economic status based on the number of years which the mother and father spent in education, and the status of their professions, which is also typically linked to income. The index is computed by an algorithm and can range from eight to 66 (Hollingshead 1975). Single parenthood was defined as the presence of a single adult in the family regardless of whether the parent was divorced, never married or widowed.

Participants and procedure

Families of children with ID, ranging from the newly born to 16 years of age, living in urban and rural communities in the south-west of Sweden, were recruited from community-based programmes providing services to the families of children with disabilities. Children and families are protected by professional confidentiality and could not be contacted in person for research purposes. The support programmes sent out a total of 691 introductory letters to all families enrolled in the programmes in the selected area who had children with a primary diagnosis of ID and/or autism. In this two-step recruitment procedure, 288 parents mailed back answer cards with their name and address, indicating that they wanted more information about the...
The control group comprised the families of 496 randomly selected children, living in the same geographical area, and having the same age and gender distribution as the study group. The randomization was carried out at the National Office of Statistics. Surveys were mailed to parents together with introductory letters explaining the selection procedure and the purpose of the study. After two reminders, the second together with a new survey, 234 control families returned completed surveys in prepaid envelopes. In 94 families, the mother answered the survey; in 22 families, the father answered the survey; and in 114 families, the mother and father answered the survey together. Eight per cent \((n = 18)\) of the children in the control families had a disability or special needs; for example, severe allergy, dyslexia and attention deficit hyperactivity disorder. These were kept in control group since the present authors wanted a comparison group who comprised the normal variation.

The children and their families

Medical providers where asked to categorize the children as either: (1) DS without autism (hereafter labelled DS); (2) ID of other aetiology than DS without autism (hereafter labelled ID); or (3) ID with autism (hereafter labelled autism). The diagnostic groups in this study were: 51 children with DS, 107 children with ID and 68 children with autism. Parents were asked to rate on a three-point scale their child’s functioning, as compared to normal peers, in five developmental domains. The domains were: (1) gross motor control (i.e. walking, running and jumping); (2) fine motor control (i.e. drawing, eating and building blocks); (3) social interaction with peers (i.e. play with peers); (4) concentration (i.e. can focus on one thing at a time and can finish tasks); and (5) speech. A rating of ‘1’ indicated ‘just as good as peers’, ‘2’ indicated ‘somewhat delayed compared to peers’ and ‘3’ indicated ‘severely delayed compared to peers’. The five domains were added to a scale ranging from 5 to 15, where ‘5’ indicated normal development in all five areas and ‘15’ indicated severely affected development in all five areas. All three groups were low functioning; the mean on the functional status measure was 10.3 for the DS group (SD = 4.3), 12.9 for the ID group (SD = 2.6) and 12.0 for the autism group (SD = 2.3). Children with autism were rated as most affected in their interaction with peers and children with DS were rated as most affected in their speech. Children with ID and autism were overall rated as lower functioning than the DS group \((F_{235.2} = 13.1, P < 0.001, \text{LSD post hoc})\).

As can be seen in Table 1, the four groups had similar demographic characteristics except that the children with DS were younger than the children in the other groups \((F_{454.3} = 11.8, P < 0.01, \text{LSD post hoc})\). When the four groups were compared with regard to proportion of single parent families no difference between groups were found but when families with children with ID were combined to one group there was a larger proportion of single parent families in the combined ID group compared to the control group \(\chi^2(1, n=460) = 5.5, P < 0.05\).

Table 1  Demographic variables in the four groups: (DS) Down’s syndrome; and (ID) intellectual disability

<table>
<thead>
<tr>
<th>Demographic</th>
<th>Control</th>
<th>DS</th>
<th>Other ID</th>
<th>Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td>Single parents [% (n)]</td>
<td>12 (27)</td>
<td>22 (11)</td>
<td>17 (18)</td>
<td>22 (15)</td>
</tr>
<tr>
<td>Male gender of child [% (n)]</td>
<td>64 (150)</td>
<td>65 (33)</td>
<td>57 (61)</td>
<td>72 (49)</td>
</tr>
<tr>
<td>Child’s age (years (mean ± SD))</td>
<td>8.2 ± 4.4</td>
<td>5.3 ± 4.1</td>
<td>8.4 ± 3.9</td>
<td>9.8 ± 3.6</td>
</tr>
<tr>
<td>Number of children in family (mean ± SD)</td>
<td>2.4 ± 0.92</td>
<td>2.5 ± 0.99</td>
<td>2.3 ± 0.83</td>
<td>2.1 ± 0.83</td>
</tr>
<tr>
<td>Socio-economic status (Hollingshead (mean ± SD))</td>
<td>37.0 ± 11.7</td>
<td>36.5 ± 13.4</td>
<td>35.2 ± 13.9</td>
<td>36.2 ± 12.2</td>
</tr>
</tbody>
</table>

Results

Financial hardship

The four groups (control, DS, ID and autism) did not differ in socio-economic status as measured by Hollingshead. There were a larger proportion of control families who owned their own home ($\chi^2(3, n=460) = 9.0, P < 0.05$). Families did not differ in the size of their housing, as measured by number of rooms. Because of a larger proportion of single parents in the ID groups, combined family income was lower overall in the three ID groups compared to the control group, but when only two-parent families were compared, no differences in family income were found across groups. Ninety-four per cent ($n=48$) of the families with children with DS, 86% ($n=92$) of the families with children with ID and 90% ($n=61$) of the families with children with autism received some amount of monthly financial assistance because of their child with disabilities, compared to 8% ($n=19$) of the control families. Eighty per cent ($n=40$) of the families with children with DS had the highest amount of monthly financial assistance (7600 Swedish kroner or US$760) compared to 45% ($n=48$) of the families with children with ID and 52% ($n=35$) of the families with children with autism ($\chi^2(3, n=224) = 20.4, P < 0.01$). Since the financial support is supposed to be based upon the caregiving demands of the child and the chronicity of the condition, it is surprising that families with children with DS (who rated their children as higher functioning than families with children with ID and autism) had more financial assistance.

Strained emotional relationships within the family

When parents were asked about the positive aspects of having a child with a disability, 44 (19%) families said that it had strengthened their family relations. Nevertheless, some of the spontaneous comments focused on strains on the emotional relationships within the family:

- It is a huge change for the entire family to have a child with a disability. The strain is great on the couple who either are tied more closely together or who fall apart if parents do not agree about the child’s needs or what is best for the child. Or if one party thinks s/he is doing more than the other. I don’t know, but I think the divorce rate is higher in families with children with disabilities because it is hard both psychologically and physically. You feel insufficient and guilty all the time!

The mother cited above indicated that, if spouses feel that one is doing more than the other, this could be a reason for family tension and conflict. Nineteen per cent ($n=43$) of the control families did not think they divided chores in the same way as other families compared to 33% ($n=16$) of the DS families, 48% ($n=49$) of the ID families and 55% ($n=36$) of the autism families ($\chi^2(3, n=448) = 46.5, P < 0.01$). The families with children with ID indicated that they thought that the mother did more of the household chores than mothers in other families. This perception of more unequal division of chores, especially evident in families with children with ID and autism, might constitute a potential source of tension among spouses.

Among the positive aspects of having a child with a disability, 14 (6%) parents said that it was positive for the siblings, who had matured. Other parents commented on the negative impact on siblings:

- An 18-year-old daughter is also in the household, but she needed to get away and live by herself because of studies. She was never left alone by the child with disabilities. But she is doing a lot better now. For 9 years, she has been an ‘extra mom’, without her I would not have survived.

There were more single-parent families among the families with children with ID in the present study, and eight mothers of children with disabilities described totally absent fathers who did not want to have anything to do with their child with disabilities, as exemplified by these two mothers:

- It would have been so much easier if we had been two active parents, especially since I have more than one child. Unfortunately, I have not had that opportunity, and sometimes, many times, I have felt disappointed that my husband has not taken his responsibility as a father. The children need him and the time he could have given them. It is a great security for children to have a dad by their side. Unfortunately there is always someone who does not care about their family and their children, especially children with disabilities.
The daddy has very scarce contact with the children. He is not seeking information about our son’s disability. The children are happy for the few times they get to visit Grandma and Grandpa, and their father shows up.

In conclusion, several families \((n = 58 \text{ or } 26\%)\) described how their family relations, including sibling relations, have grown stronger and more intimate because of their child with disabilities. However, there were also descriptions of strained emotional relationships because of the child with disabilities, and families with children with ID or autism more often thought they divided chores differently than other families compared to families with children with DS and control families. Several families described both positive and negative changes in the family.

**Modification of family activities and goals**

As Table 2 shows, the mothers of children with ID were more often not employed or were not employed full time compared to the control mothers (mothers who were temporarily on parental leave or who were studying were counted as not employed; the very low percentage of mothers of children with DS who worked full time was a result of the lower age of children with DS since many of these mothers were still on parental leave). Eighteen per cent \((n = 10)\) of the mothers with children with DS had, in periods, given up work altogether to take care of the child with disabilities, compared to 27\% \((n = 29)\) of mothers of children with ID, 41\% \((n = 28)\) of mothers of children with autism and 8\% \((n = 19)\) of control mothers \(\chi^2(6, n=444) = 78.9, P < 0.01\). No difference in work situation was found between the fathers in the four groups. Both the mothers and fathers with children with ID more often perceived that they did not have the same opportunity as the control parents to participate in paid work. The mothers’ reasons for not perceiving themselves as having the same opportunity as other mothers to participate in paid work were: (1) the child required more care, which made the mother more tired and less energetic at work \((n = 36)\); (2) difficulties getting child care that met the child’s needs \((n = 28)\); (3) the child’s need for structure and routine made it hard to be flexible at work \((n = 21)\); (4) the mother had to leave work often because the child was often ill or needed to go to appointments \((n = 19)\); and (5) the mother wanted to be with the child as much as possible \((n = 14)\). The most often mentioned reason for fathers not to perceive themselves as having the same opportunity to participate in paid work was that the child’s need for structure and routine made it hard to be flexible at work \((n = 15)\). Mothers who had adjusted their work situation because of their child most often had reduced their work hours or worked part time; it was also common to have changed work schedule and to work from the home. Among fathers, the most common change in the work situation was a change of schedule.

When parents were asked about positive changes because of the child with disabilities, the most common answer could be summarized as ‘new views of life and what is important in life’ \((n = 91, 41\%)\), suggesting that many parents had accepted and adopted new goals in life. Many parents described in positive terms how they had actively changed their lives according to the needs of their child with disabilities:

For us, the child with disabilities has, of course, changed life. We compare it to working through a sorrow. The healthy child we did not get has been lost. This affects the relations between spouses, siblings, family and friends. We change our positions and values, and life gets new and important goals. Life goes on with these new conditions.

Our life is directed much by the needs of our child. We have tried to arrange life after her as well as possible and on everybody’s terms. We are doing fine, and do not miss a more active or outgoing life much, but it is a balancing act to meet everybody’s needs.

In conclusion, mothers with children with ID or autism found it more difficult to participate in paid work compared to mothers of children with DS, but changes in work situation and changes in what the family perceived as important in life was common across all three ID groups. The changes in life goals where usually described as something positive, and there were very few negative comments about the modification of family activities and goals.

**Restricted social life**

As Table 2 shows, the majority of the ID and autism families did not feel that they had the same possibil-
<table>
<thead>
<tr>
<th>Variable</th>
<th>Control</th>
<th>Down's syndrome</th>
<th>Intellectual disability</th>
<th>Autism</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Percentage</td>
<td>Number</td>
<td>Percentage</td>
<td>Number</td>
</tr>
<tr>
<td>Mother not currently employed outside home</td>
<td>28</td>
<td>62</td>
<td>60</td>
<td>30</td>
</tr>
<tr>
<td>Mother employed full time</td>
<td>33</td>
<td>75</td>
<td>6</td>
<td>3</td>
</tr>
<tr>
<td>Father not currently employed outside home</td>
<td>13</td>
<td>28</td>
<td>19</td>
<td>8</td>
</tr>
<tr>
<td>Father employed full time</td>
<td>87</td>
<td>177</td>
<td>76</td>
<td>32</td>
</tr>
<tr>
<td>Mother does not feel she has the same opportunity as other mothers to participate in paid work</td>
<td>10</td>
<td>24</td>
<td>34</td>
<td>16</td>
</tr>
<tr>
<td>Father does not feel he has the same opportunity as other fathers to participate in paid work</td>
<td>2</td>
<td>4</td>
<td>21</td>
<td>9</td>
</tr>
<tr>
<td>Mother has adjusted her work situation</td>
<td>39</td>
<td>87</td>
<td>61</td>
<td>30</td>
</tr>
<tr>
<td>Father has adjusted his work situation</td>
<td>13</td>
<td>28</td>
<td>26</td>
<td>11</td>
</tr>
<tr>
<td>Same possibilities for recreational activities as other families</td>
<td>79</td>
<td>183</td>
<td>58</td>
<td>29</td>
</tr>
<tr>
<td>Same possibilities for vacation as other families</td>
<td>74</td>
<td>109</td>
<td>61</td>
<td>31</td>
</tr>
<tr>
<td>Extra household work</td>
<td>10</td>
<td>24</td>
<td>34</td>
<td>17</td>
</tr>
<tr>
<td>Extra emotional support</td>
<td>7</td>
<td>17</td>
<td>62</td>
<td>31</td>
</tr>
<tr>
<td>Mother has had time for herself during the week</td>
<td>63</td>
<td>145</td>
<td>46</td>
<td>23</td>
</tr>
<tr>
<td>Father has had time for himself during the week</td>
<td>60</td>
<td>123</td>
<td>65</td>
<td>26</td>
</tr>
<tr>
<td>Spouses have had time together without kids during the month</td>
<td>44</td>
<td>102</td>
<td>32</td>
<td>16</td>
</tr>
</tbody>
</table>

*Key: (1) 3 (n = 444) = 20.1; (2) 6 (n = 437) = 30.0; (3) 3 (n = 4.92) = 41.6; (4) 3 (n = 4.92) = 47.9; (5) 6 (n = 445) = 47.9; (6) 3 (n = 4.92) = 10.6; (7) 3 (n = 4.92) = 131.5; (8) 15 (n = 400) = 375.2; (9) 2 (n = 226) = 18.1; (10) 2 (n = 226) = 12.1; (11) 3 (n = 453) = 21.7; and (12) 6 (n = 455) = 16.9.
ities for recreational activities and vacation as other families. Difficulties with finding a baby-sitter or suitable activities for the whole family were the most often cited reasons for not having the same possibilities for recreational activities in families with children with ID. Among the control families who indicated that they did not have the same possibilities for recreational activities, financial concern was the most common reason. The same pattern appeared when analysing why families did not have the same possibilities for vacations as other families. The ID families most often found it hard to find suitable places and activities to go during their vacations, while control families most often indicated that it was their financial situation that hindered them the most. Twenty-one per cent (n = 41) of the control families thought it was hard or very hard to find a baby-sitter compared to 24% (n = 12) of the families with children with DS, 56% (n = 60) of the families with children with ID and 60% (n = 41) of the families with children with autism \( \chi^2(15, n = 411) = 86.7, P < 0.01 \).

Although 34 (15%) families mentioned meeting new people as one of the positive aspects of having a child with a disability, several parents commented on their restricted social life:

The energy for social life is limited. Work and the child take almost all time.

It is hard to have a social life with other families. We can feel that they avoid us, they feel bothered.

To go out a Friday or Saturday night is not easy. It has to be planed with respite. The possibility of meeting a new partner is very limited since you are so tied up.

In conclusion, finding energy for and suitable forms of social and recreational activities was a major concern for families with children with ID or autism. These families had more restricted social lives than families with children with DS and control families, mostly because: (1) they found it difficult to find suitable activities for the whole family; and (2) they found it very hard to find a baby-sitter for the child with disabilities.

Time restrictions

As seen in Table 2, the children with ID and autism needed more extra help in all areas than children with DS and control children. The most frequently mentioned extra household work was more cleaning and washing than usual, followed by unusual wearing and tearing of clothes, and repairs which had to be done as a result of the destruction of toys, wallpaper or furniture, for example.

As Table 2 shows, there were fewer mothers in the three ID groups who had had any time for themselves during the past week compared to the control group, with mothers of children with autism having the least opportunity for time alone. There were also fewer ID families where the spouses had had time together without children during the last month. Among those families who had had time for themselves and for each other, the number of hours did not differ between the ID groups and the control group. Family members and relatives were by far the resource mostly used when parents in all groups needed time for themselves. In the control group, up to 24% of the children could take care of themselves for a couple of hours, which was not possible for any of the children with disabilities.

Sixty-nine per cent of the families in the ID group had respite care, evenly distributed among the three groups. Out of the families who did not have respite, 32 families said that they did not have a need for respite care, 15 families thought that their child was still too young, nine families wanted to take care of their child themselves but wanted help with cleaning and laundry, and five families wanted respite but had not received it yet.

Several families commented upon time restraints related to the interaction with the support system and related to siblings:

To fill out forms and admissions, talk to people on the phone, etc. for our son takes enormous amounts of time. We estimate that we would need an administrator employed half time to do that work.

As a mother, I feel very sorry for our daughter [a sibling] with whom I do not have the time I would have wished for. I often want to split in two to be able to satisfy both of their needs. I am also fearing that this will get worse as he [the son with disabilities] gets older and demands more of me.

Some families offered advice on how to better support families to decrease their time restrictions:
I think all families with children with disabilities need respite care a couple of hours every week, very early on. It takes time to let a stranger take care of your ‘fragile’ child, but if there are siblings in the family, it should go without saying. The support workers should really stress this and encourage families to use it.

The support available is inflexible. The child can have respite care, but if the child doesn’t do well when left with others, the family can’t get any practical help. The result is that I have to look after him at the same time as I clean, do the laundry, cook and everything else. Things that cannot be done with him around have to be done at nighttime. I often iron and clean until 2 at night. I wished I could afford help with housekeeping!

The children with disabilities, and especially those with ID or autism, indeed needed more direct caregiving than control children, but several parents also mentioned secondary time restraints caused by contact with professionals.

Contact with professionals

Families were asked to check how many of 17 listed professionals they had been in contact with during the past year, and how satisfied they had been with the contacts. Control families indicated contact with 2.6 professionals compared to 8.3 in DS, 9.5 in ID families and 8.3 in autism families \((F_{4,173} = 228.0, P < 0.01)\). Nevertheless, 57\% \((n = 106)\) of families with children with ID indicated that they would have wanted more contact with speech therapists, doctors, physiotherapists and psychologists. Overall, parents were satisfied or very satisfied with their contact with professionals.

Twenty (9\%) families had written comments on support services. Most of these comments dealt with the struggle of getting the help the child and the family needed, and that the parents felt they were entitled to get:

Something that I have learnt is that the laws of society are worth nothing. Our ‘rights’ are not worth the name. Instead of helping us, the authorities fight against us. There is no justice in the country. How much help and support you get is totally dependant on where you live!

We want more contact with professionals. We get much too little information about where our son with his disability should be placed in day care, pre-school, special education, etc. You have to figure everything out yourself and you feel very lonely. It sounds so nice with children within LSS [the law of service and support for people with disabilities], but everything has to be fought for. The power you need to take care of the child is wasted on finding out about services, calling and getting angry.

However, there were also positive comments about the support system:

We have been so well taken care of ever since the beginning. Everybody has been caring, understanding and supportive, and that is the most important thing.

We have never mind paying the high taxes in Sweden, and now we can really see where the tax money goes.

Overall, families seemed to be quite satisfied with their contact with specific professionals, but several families feel very strongly that the support system that they thought they could count on is not living up to its promises. Several parents describe how getting the right support can be a struggle.

Mourning and depression

When parents commented on their mood, most attributed depressed mood to work overload and too little time for themselves:

It is very demanding always having to fight for your rights against the community. It takes up so much time and energy, which you really need at home. I often feel insufficient as a mother, wife and in my work. I am often sad. My marriage is cracking. I always have to be there for everybody else. I never have time for myself.

A short description of how it feels. I don’t remember when I was 20 or 25. There are no longer any pictures about the future. Everything is just right now in a strange kind of vacuum, where every day looks just the same as yesterday. Sometimes our home feels like a prison, a place where my entire person is just mother, teacher, therapist, housekeeper, etc. all in one. That which is just me has
kind of been suppressed. My own needs have slowly faded away until there is just a surface of no emotions left. I can’t remember when I was sad or angry last. Despite this, I am not at all bitter; I am much more grateful for everything today than previously. Inside there is joy, the joy of our children, the best thing in the world.

The child her or himself was usually seen as a buffer against depression, as reflected by the many parents who mentioned that the child and her or his personality was one of the positive things about having a child with disabilities ($n = 52, 23\%$):

It is hard to be a parent of a child with disabilities. You cry and laugh. But you put up with a lot because you love him so much!

Other families ($n = 33, 15\%$) mentioned the joy when the child made progress, even when this was small. Some parents ($n = 29, 13\%$) also indicated that the experiences they had gained through parenting their child with ID had made them stronger and given them renewed self-confidence and feeling of meaning in their lives. Twenty-seven (12\%) parents could not mention anything positive about having a child with a disability.

In conclusion, most families described positive things about having a child with a disability, and many parents described how their child is the joy in their life. Despite this, several parents described feelings of depression, most often attributed to work overload, and lack of time for themselves and their interests.

Discussion

The aim of the present study was to explore the life situation of parents with children with ID in Sweden compared to that described in studies from the US and UK, for example. Taken together, the parents in the present study to some degree described most of the situations among parents is great. Most parents (88\%) described positive aspects of having a child with disabilities, with 41\% stating that they had adopted 'new views of life and what is important in life', which is consistent with other studies (Scorgie & Sobsey 2000). Many of the changes which families had made in their lives were described as positive such as 'living a calmer life', 'appreciating the small things in life' and 'taking better care of each other'. As indicated in other studies (Beresford 1994; Knox et al. 2000), their strong love and affection for the child with disabilities, as well as the joy of seeing the child making 'small' achievements were described as something positive which made the parents put up with a lot.

Sweden is a country with relatively low variation in income and a tax system designed to further level out income differences. Families with children with disabilities receive financial assistance aimed at making up for additional costs and lost income. The absence of income differences between families with children with ID and control families, and the few comments about the financial situation found in the present study, indicate that the macro-system in Sweden has minimized the financial strain experienced by parents of children with ID. However, it is noteworthy that families with children with ID and autism, who were lower functioning and needed more help than children with DS, received less financial support than families with children with DS. This indicates weaknesses in the administration of this financial support.

Restricted social life and time restrictions seem to be the two most evident and bothersome stressors for Swedish families with children with ID, and especially for those with children with ID and autism. There may be several explanations for this. Since the 1960s, there has been a strong call for women to take part in paid work, driven both by the feminist movement and a need for women’s labour forces in the 1960s when Swedish industry was booming (Moen 1989; Sundström 1991; Haas 1992; Haas 1993). Two working parents is the norm in Swedish society, both by choice and necessity (Myrdal 1947; Moen 1989; Sundström 1991; Haas 1992; Sandqvist 1992; Haas 1993; Gatmon 1999). Despite the affordable high-quality day care available to all children in Sweden, some parents with children with ID in the present study described how they have trouble finding child care that fits the child’s needs. If you want or need to take part in paid work, but do not feel confident that your child’s needs are being met at day care, there may be a conflict of interests that may result in guilt and stress in the parent. In Shearn & Todd’s (2000) UK study, the mothers also described problems with day care as one of the major obstacles to their participation in paid work, but their worries

were not so much the suitability of the day care as the total absence of available day care.

The double workload of paid work and child-care demands faced by parents has been shown to affect mothers' stress levels in particular. Mothers tend to wind up after work when child-care and household demands have to be taken care of, while fathers have been found to wind down when they leave work (Frankenhaeuser 1991). This gendered pattern is perhaps especially evident in the families of children with ID, and can explain the consistent findings of higher stress levels and more depressive symptoms in mothers of children with ID than in fathers (Beckman 1991; Olsson & Hwang 2001). The intense and long-term caretaking demands and increased household work in families with children with ID, and especially those with children with ID or autism, may result in stress reactions, and feelings of guilt and insufficiency, as several parents described. Many parents viewed the monthly financial assistance as a chance to reduce working hours, as could be seen in the fewer mothers with children with ID who worked full time. For some parents (mostly mothers), this is a way of reducing the stress caused by the double workload, but if the parent (mother) feels rewarded by and committed to her or his work, and views working as one way of following personal aspirations, reducing work involvement may create frustration.

Services to families with children with ID do include respite care, but several families in the present study would rather have help with housekeeping to be able to spend quality time with their children. Adding housekeeping to available services might free some valuable time and energy to parents who want to continue their work involvement. As in Shearn & Todd’s (2000), the unusual time demands were one of the major threats to mothers’ equal opportunity to take part in paid work. Overall, the macrostructure of Swedish society helps the mothers of children with ID to remain in paid work, but not to a satisfactory level. Improvements are needed in the areas of child care, so that it successfully meets the need of children with ID, and housekeeping services, to support those mothers who choose to work.

Time restraint was mentioned as one reason why families with children with ID did not have the same opportunity for social life and recreational activities as others; the lack of appropriate activities and available babysitters were other reasons offered. Thus, helping families to find activities which both the child with disabilities and the other family members can enjoy should be a prioritized task for support workers. It is important to keep in mind that many children with ID will not be able to take care of themselves, even for shorter periods of time, which makes it hard even for parents of teenage children with ID to get time for themselves. Even though relatives were found to be the most frequently used resource in the present study as well as in others (Heller et al. 2000), well-functioning respite care is imperative if parents are to be able to get valuable time for themselves. Supporting parents to take time for themselves is important, but most parents will not do this if they are not confident that their child is well taken care of, which further emphasizes the importance of well-functioning respite care.

The interpersonal relationships in families with children with ID were found to be both strengthened and weakened by the presence of a child with disabilities. As shown in previous studies (Grant & Whittell 2000; Scorgie & Sobsey 2000), many families perceived that the care of the child with ID had made the family relations grow stronger and more intimate. Only a few parents commented on strained relations between spouses, and most of these were single mothers experiencing the stress of totally absent fathers. Absent fathers are not unique to families with children with ID, but being a single parent to a child with special needs might increase the risk of experiencing high stress and depressive reactions. Grant & Whittell (2000) also identified single parents with children with ID as an especially vulnerable group because of a limited repertoire of coping strategies. It is important to find ways to support marital relations when this is needed and to help fathers to get as involved as possible in the daily care of the child in order to strengthen the family unit. If fathers are actively involved, the possible tension of the mother experiencing inequality in the division of chores may decrease, as will the possible threat of the father losing contact with his child after a divorce.

As found elsewhere (Fisman et al. 2000; Saxena & Sharma 2000; Van Riper 2000), the impact on siblings does not point in a clear direction either: some parents think that it is positive for the siblings to have a brother or sister with a disability, while others feel guilty about not having enough time to satisfy the needs of the other siblings. Again, having two parents...
active in child rearing probably minimizes the possible negative impact on siblings by assuring that every child in the family has sufficient parental contact.

The conflicting findings around services are consistent with a study by Axtell et al. (1995). The above authors also found that parents overall were positive in their ratings of services, even though many families reported unmet service needs in certain areas. The results of the present study can be interpreted in several ways. Those parents who described negative experiences may just have been unfortunate, or they are demanding parents who will never be satisfied regardless of how much help and support they get. It is also possible that the support system is not as easy to navigate as it should. There is support in previous research in Sweden that parents feel that they do not get services easily, but rather, that they have to actively claim their right to them (Högberg 1996). Some parents are declined services which they actually are entitled to because the community does not have the resources to provide the service. In addition, parents in Sweden probably have a different expectation about support services than those in many other countries because they count on the welfare state to help them in times of trouble. Parents in Sweden probably expect that necessary services should be available in the community without too much of a fight. A third explanation is that parenting a child with disabilities, and especially a child who also has behavioural problems, will inevitably cause stress and needs in families which services can never fully prevent or meet satisfactorily. As in previous research (Fisman et al. 1989; Ryde-Brandt 1990; Dumas et al. 1991; Axtell et al. 1995; Sanders & Morgan 1997; Dykens & Hodapp 2001), the present study consistently showed that the parents of children with ID and autism experienced more stressors and restrictions in their lives than parents of children with DS, most probably because of a higher prevalence of problem behaviours in these children compared to children with DS (Hodapp et al. 1997; McIntyre et al. 2002).

It might seem discouraging that parents with children with ID in Sweden experience most of the same stressors as parents in other countries despite the relatively high level of support available to families. Does this imply that support doesn’t matter? The present authors feel confident that that is not the case, but also that they still have a lot to learn from families regarding ways of delivering services. Having to actively claim and go through investigations and evaluations to be eligible for support is perceived as stressful and a violation of integrity by many parents, and these procedures should preferably be kept to a minimum. Since the other privileges available to all parents in Sweden (i.e. the child allowance and the parental leave) do not include an application and evaluation process, but come automatically, why should the support to families with children with disabilities be different? One important thing for parental well-being and satisfaction with services is that parents perceive that they have control over services and their own life situation (Knox et al. 2000), something which the present procedure of support delivery in Sweden does not seem to give them. Whatever support is offered, the parents of children with ID will probably always indicate that they have more stress in their lives than control parents since the birth of a child with disabilities is a stressor that can never be eliminated through services. The potential stressor will always be there, and parents will, depending on a number of different variables, be more or less vulnerable to that stress. Even if the support system could never totally eliminate the potential stress associated with caring for a child with ID, it can surely facilitate the family’s situation and increase the families possibilities of choosing the best way for their family to live with their child with ID.

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