Young adults with intellectual disability recall their childhood

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Abstract
Eleven young adults with an intellectual disability were interviewed for this exploratory study aimed at charting their experiences of growing up in homes where at least one parent had the same or a similar disability. Two main themes emerged from the interviews. Firstly, a clear majority of the young adults had positive experiences of family life during their upbringing, as expressed especially through their memories of their grandparents. Secondly, the study participants all described experiences of being bullied and harassed outside the family context. The results obtained in this study highlight the importance of the parents, the family, and informal networks in the upbringing of these children. The study also considers the consequences that the study participants’ negative experiences of peer contacts and their sense of exclusion might have for their prospects in later life.

Keywords
childhood, family, intellectual disability, networks

Background
Research on children growing up with parents with intellectual disability (ID) has remained very limited, particularly from the children’s perspective. A research review by the Swedish National Board of Health and Welfare (2005) found few studies that had examined the children’s situation and few that had included children or adult children as informants about their own upbringing.

In one retrospective study (Booth and Booth, 1998), it was found that almost all adults with experiences of being brought up by parents with ID perceived their relations with family members, especially their mothers, as positive. The relationships with the parents were described as
loving and respectful, giving rise to feelings of gratitude. None of the study participants, however, described their childhood as an easy one. Most of them had experienced difficulties in their relations with non-family members in their social environment. The majority of the participants reported having been subjected to harassment and bullying by peers, neighbors, and others they encountered in their daily life, experiencing also intimidation, threats, and physical abuse. Similar findings emerged from a study by Cleaver and Nicholson (2007). The social work case files they examined revealed that both children and their parents had frequently been exposed to harassment and abusive behavior from neighbors and others around them.

The findings by Booth and Booth (1998), according to the authors, can be explained by their study participants’ exclusion and isolation from society and the discrimination experienced by the whole family. The study showed that the informants had developed various coping strategies to deal with such challenges, suggesting that children who grow up in harsh environments also need to be studied in terms of their ability to develop resources of resistance and ‘resilience’ (cf. Rutter, 2001).

Children’s and young adults’ experiences of mobbing, betrayal by friends, social exclusion, and lack of informal networks and close friends have been described in other studies (e.g. Gustavsson, 1998; Tideman, 2000). In a longitudinal study by Faureholm (2006), it was found that young adults had experienced their childhood differently depending on whether they were female or male. Young women more often reported having had a sense of being expected by professionals to help their parents with everyday chores and manage tasks at home. Unlike the boys, they were also expected by their environment to be able to care for others. This, according to Faureholm, could be interpreted as indicating a process of ‘parentification’ (Becker et al., 1998) where the girls tend to take on responsibilities in everyday life that are normally expected of adults. The boys, on the other hand, were seldom expected to help their parents or take care of household tasks. They were also more outward oriented, reacting more strongly to their environment and often in conflict with others. This behavior drew the attention of the professionals more to the boys, with the consequence that they also received more support from them.

In response to these previous findings, this article examines experiences that young adults with ID have of their childhood, with particular focus on their relationships and interactions with their family members and on their informal and formal broader social networks.

**Methods and data**

The young adults participating in this study were recruited through professionals working at adult habilitation centers \((n = 8)\) and special schools \((n = 3)\) in the region of Västra Götaland in western Sweden. The agencies and institutions in question have been tasked to, among other things, provide services and support for persons with intellectual disability according to the Swedish Act Concerning Service and Support to Certain People with Disabilities. The study participants were to be between 18 and 25 years of age, have an intellectual disability, and have lived most of their childhood with at least one parent having the same or a similar disability. Thirteen young adults were invited to participate in the study, with 11 of them accepting to do so. The two who declined did not provide any particular reasons for their not wanting to participate. Those who accepted to participate were aged between 18 and 32 years, as described in Table 1.

Two of the participants were women older than 25. Upon learning of the project from their younger brother, they, on their own initiative, volunteered to join it, and, as it was considered unethical to refuse their request, they were included among the interviewees.
The time and location of the interviews were determined by the participants. Consequently, most of the interviews took place in locations familiar to them. A few interviews were conducted in the interviewees’ homes. All interviews were face-to-face and conducted with one participant at a time, with all study participants being interviewed twice. The first of the two interviews was conducted using an interview guide to help thematize different issues and topics related to upbringing, everyday life in today’s society, relations in the families, informal and formal networks, and the like. During the second meeting, questionnaires were used to help capture the participants’ different perspectives on their everyday life and in their social networks, with qualitative discussions following the filling of the questionnaire forms that extended beyond their scope. The discussion in this article covers all the qualitative data gathered from the two interview rounds that concerned the study participants’ experiences of their upbringing.

The interviews were digitally recorded and transcribed from audio files. The analysis of the interview notes and transcripts revealed different themes in the study participants’ stories, arising from the young adults’ dominant narratives of upbringing (cf. Reissman, 2001). The primary focus here was on understanding the participants’ experiences of their childhood. Specific utterances were identified in the different interviews that captured patterns and distinctive characteristics in the young adults’ narratives. To better make sense of them, the interviewees’ statements and descriptions were analyzed relying on Antonovsky’s (1987) theory of a sense of coherence, utilizing concepts such as manageability, comprehensibility, and meaningfulness, and on the theory of resilience (Rutter, 2001).

The quotations from the interview material as used in this article were chosen to highlight the study participants’ reasoning and to point out events, phenomena, and/or processes illustrating the conditions of their upbringing. For the sake of brevity, digressions from the subject have been

<table>
<thead>
<tr>
<th>Study participant</th>
<th>Age</th>
<th>No. of siblings (Y = younger, O = older)</th>
<th>Family structure</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adam</td>
<td>22</td>
<td>5 Y</td>
<td>Two-parent family with 6 children</td>
</tr>
<tr>
<td>Gunilla</td>
<td>19</td>
<td>1 Y</td>
<td>Two-parent family with 2 children</td>
</tr>
<tr>
<td>Gunnar</td>
<td>18</td>
<td>1 Y</td>
<td>One-parent family with 1 child</td>
</tr>
<tr>
<td>Gustav</td>
<td>21</td>
<td>1 O, 1 Y</td>
<td>One-parent family with 3 children</td>
</tr>
<tr>
<td>Johanna</td>
<td>21</td>
<td>1 Y</td>
<td>One-parent family with 2 children; from age 12 on in foster family</td>
</tr>
<tr>
<td>Pernilla</td>
<td>19</td>
<td>–</td>
<td>Two-parent family with 1 child</td>
</tr>
</tbody>
</table>

*Participants from Svensson family*

| Julia             | 32  | 3 Y                                 | Two-parent family with 7 children |
| Jennifer          | 31  | 1 O, 3 Y                            |                                |
| Jonas             | 22  | 3 O                                 |                                |

*Participants from Gunnarsson family*

| Bodil             | 23  | 2 O, 1 Y                            | Two-parent family with 4 children; periodic stays with foster family |
| Birger            | 25  | 1 O, 2 Y                            |                                |

Table 1. Study participants and their families during childhood
removed, with omissions indicated by ellipses. In translating the quotes from their original Swedish into English, particular care was exercised to preserve the original character and content of the interviewed young adults’ own words.

The study methods were approved by the Regional Ethical Review Board in Gothenburg, Sweden. Given the fact that the interview sample was relatively small and all the participants came from one, fairly narrowly defined region in the country, the data on the participants are described in a manner aimed at preserving confidentiality. In this study, de-identification was considered imperative, for which reason all interviewee names have been changed, and situations that could be perceived as identifying have been omitted from the presentation, along with all names of localities and other such potential identifiers.

The study can be regarded as a contribution towards a better understanding of the perspectives and perceptions these young adults have concerning their own childhood. The fairly limited nature of the study, however, does not allow any general conclusions to be drawn.

**Results**

**Family**

*Childhood, parenting, and relations with parents during upbringing.* In the interviews, the dominant story that emerged was that of a good family life the interviewees had enjoyed during their upbringing, being well cared for by their parents. This became particularly apparent in the way the interviewees described their relations with their parents. Most of them reported having had close relationships with their parents during childhood. The parents were almost uniformly described as having been supportive of their children in various concrete ways. Such positive experiences had clearly come to color the interviewees’ own views of children’s needs and what good parenthood consisted of. As Pernilla, for example, put it:

> [P]arents should love and enjoy their child … They should be ready to help if the child needs it, be a role model and also accept the responsibility for their child … Children need security and comfort, affection and tenderness; they need to be loved and told from the beginning what you should do, so you understand what is right and wrong.

The point that parents should help their children to become more independent and support their development into autonomous individuals was described by other study participants as well. Good parenting was also understood to mean that parents ‘stick together’ and do things together with their children. The interviewees stressed that parents need to play with their young children and talk with them. Most of them described having had emotionally close relationships with their parents, stating that the parents had been important to them when they were young children. In most of the narratives, however, the relationship to the two parents had been somewhat different, with different things expected from each. The interviewees seemed to have experienced their mother as the one they could talk to more easily. Jonas, for instance, spoke of his mother as someone who was:

> Amiable and good to talk with. My father, he was funny and determined, but it was not so easy to talk to him, if you know what I mean.
Bodil told that she talked mostly with her mother, her father being apparently less than accessible at times:

I still have this feeling of safety with them [the parents]. I could talk about anything with them . . . especially my mother, but with my father, too, when he was calm.

According to Bodil, her father could become very angry and violent, and on one of those occasions it even happened that he hit Bodil’s brother Birger. Birger, who also participated in the study, could still remember when and how this happened:

. . . but once when I was there [in the garage] with him and he was looking for a tool but couldn’t find it, he got really upset and beat me up and stuff.

Experiences of violence during upbringing were reported by another participant, too. Julia had been repeatedly beaten by her parents, especially her mother. This happened most often when, contrary to her parents’ express demands, she did not want to take care of her younger siblings. This need to take on responsibility for her younger siblings made Julia feel like she had not had any childhood at all, having been forced to become an adult too fast.

Contrasting with Julia’s description, however, two of her siblings, who also participated in this study, depicted the parents as caring. They indicated that they had been taken good care of by their parents. As Julia’s brother Jonas summed it up:

I feel that my parents gave me a good foundation.

This, certainly, was in perfect accordance with Julia’s description of the conditions in which her siblings grew up. According to Julia, she took care of them, protecting them from the parents, with the result that neither of the siblings interviewed for this study reported having ever been beaten at home.

Johanna, for her part, had experienced parental neglect during childhood. According to her, she and her brother often lacked food at home. Her clothes were often too small, inappropriate for the season, or dirty and shabby. Johanna also remembered having no general rules set for the children at home, with her and her brother often staying out and playing at night. Her mother simply disappeared at times, leaving the children alone even for several days in a row without any food or care from another adult. When Johanna was 12 years old, she and her brother were placed into separate foster homes. Yet, Johanna had always kept in contact with her mother, even though she never thought of moving back home to stay with her; she simply had felt the foster home to be a safer place to live in.

Relations with siblings. As appears from Table 1, most of the study participants had siblings. In the interviewee narratives about their upbringing, the importance of siblings was brought up in various connections. The siblings were frequently referred to as friends who often played together with the study participants in their childhood. Jonas, for example, reminisced on this very fondly:

. . . the atmosphere was great, we were out a lot and played together, all of us . . . in the backyard, so we spent a lot of time outside.

The study participants with families with more than two children reported having had different relationships with different siblings. Here the participants’ narratives also included accounts of
conflicts between siblings. Some of the interviewees remembered having constant quarrels with their siblings, while some of them had had siblings who frequently quarreled with one or both of the parents.

**Childhood networks**

**Informal networks.** Most of the participants described having had a close relationship with their grandparents or other relatives during their childhood, something they considered as important for their upbringing. This importance was twofold: on the one hand, the grandparents and/or other relatives provided support for the parents in these families; and on the other hand they created close emotional relationships with the children as young adults. Relatives could, for instance, support the parents by looking after the children so that the parents could rest or take care of other things needing attention. At the same time, they also supported the children, by playing with them and doing things together with them that helped foster a close relationship. Gustav, for example, recounted about his grandfather that:

> He often used to take me along with him. I liked him a lot. . . . We went out into the woods or trained together, things like that. I liked it a lot.

It was more common that the study participants referred to the importance of grandparents and adult relatives in their childhood than that of their peers. When asked about their relationships with their friends, the participants usually stated that they had had one or two important friends. Some of these, however, were cousins or other relatives of the same age.

In their descriptions about their family networks, the participants reported that their families often met with their relatives during weekends and holidays like Christmas or during summertime. The parents, however, seemed to have seldom met with personal friends or invited friends to their homes.

**Formal networks and interaction with professionals.** Most of the participants reported having received no support from professionals for their family. Only the siblings Birger and Bodil remembered having received such help. The presence of the professionals in their case was perceived as something positive, with Birger describing it as follows:

> I liked it when they came to our home. They came there to take care of us [children]. We did different things with them: we painted, we watched TV, and so on. I thought it was nice; I liked it.

As noted earlier, both Birger and Bodil had a contact/foster family with whom they stayed during different periods of their childhood. As Birger reported:

> We lived mostly at home. But mom and dad sometimes needed to rest and stuff like that, and that’s when we went and stayed with them [the contact/foster family] . . . Sometimes we stayed with them for a few weeks when mom and dad had to rest a little longer. Sometimes it could be a couple of months, and once we stayed with them for one year.

Even at the time, both Birger and his sister had been aware of the reasons why their family received this form of support: as they put it, their parents had requested help because they felt that they needed to rest and ‘charge their batteries’ (Birger). They perceived this to have been a good solution for everyone in the family, both the children and the parents. They described
their foster home as a tranquil environment in which they could feel at ease, even though Birger was quick to add:

It just felt a bit strange, to have two families, so it did feel a little bit weird.

Even if most of the participants could not recall having received any support within their home environment, some of them expressed appreciation for the support they received from their teachers at school. As Jonas described it:

I did get a lot of help from the school, with the readings and stuff. They were always very supportive. They saw what I needed.

Not all participants, however, found their teachers supportive, and, for different reasons, some of them even mistrusted their teachers. Adam, for example, told that one of his teachers reported him to social services:

They said that my parents didn’t care for me. They said that I got no love [from them], no intimacy, things like that.

Adam, however, claimed that this was a misperception and that his parents in fact did care about him very much. He further reported that the assessment by the social services proved a major distraction from his school work, something that he felt very sorry and upset about. Yet, as he described it, in the end ‘we [Adam and his parents] won anyway’.

In some of the stories recounted by the interviewees, the teachers were presented as having treated them unfairly. This was so especially among the male participants in this study: they reported frequent experiences of having been unjustly blamed by their teachers for incidents like schoolyard fights and the like.

Interaction with peers in the school context

All the participants in this study had gone to school following the Swedish special needs school curriculum. Some of them had been integrated in regular classes with additional help provided to them, while the majority of them had attended separate classes for special needs children in locations outside the regular school or sharing the same buildings with it.

While the study participants remembered their school days differently, when they spoke of their experiences of being at school, their perceptions were predominantly negative and conveyed through descriptions of being bullied.

Experiences of being bullied. All of the study participants reported having been bullied by their fellow pupils from primarily the regular school. Jonas’s experience was typical in this respect:

I was bullied a lot in fifth and sixth grade. And when I got to seventh grade, there was this guy who tried to flush my head in the toilet.

With a few exceptions, the interviewees reported that their teachers remained unaware of such incidents or failed to notice the ongoing bulling. Most of them had not informed their parents or teachers of what they were subjected to, fearful as they had been of their tormentors’ carrying out their threats of something even worse happening if they did so.
Among the interviewees, the women’s narratives about bullying differed from those of the men. The women described themselves as having been verbally bullied while all the men had experienced both verbal bullying and physical abuse from pupils from the regular school as well as the special school. Gunnar described this as having mostly been about:

... ridiculous things ... like happening to be in a wrong crowd ... [or] hanging out with the not so popular people.

Gunnar also described his efforts in trying to withdraw and stay away from those who bullied him, for the most part succeeding. He further reported his experience that telling the teachers had no effect on the situation, as those bullying him simply denied doing so, just laughing at him. Similar accounts were produced by almost all the other male interviewees.

**Experiences of being the abuser.** In the narratives of the young adults interviewed for this study, especially the men among them, descriptions of frustration, anxiety, and stress were prominent. Sometimes these feelings were described as having given rise to a tendency to be violent to others and/or self-destructiveness. One of the male interviewees recalled having been violent since preschool, while others reported that their violent behavior had developed during later years, especially in their teens.

In these descriptions, the violent behavior emerged as a protective strategy. The male study participants stressed that they needed to protect themselves against physical abuse by others. By using violence, they could earn for themselves the respect of others. The male interviewees reflected that this brought a certain feeling of satisfaction that helped them to build self-confidence. At the same time, they had remained keenly aware that hurting others was not acceptable behavior.

**Self-destructive behavior.** Some of the young adults interviewed for this study described episodes of depression and various forms of self-destructive behavior often accompanying such periods. In this connection, even attempts to commit suicide were reported by some of the participants. One of them described how he:

... broke down, gave up, and tried to kill myself. But the police showed up and took me and drove me to a psychiatric clinic. I was there for two months but I was released too early. Right after I got back home I tried to do the same thing again.

Even within the limited sample of this study, the issue of suicide or suicide attempts emerged as a prominent topic in the accounts of the young adults interviewed.

**Discussion**

The aim of this exploratory interview study was to capture the experiences and reflections that young adults with learning disabilities had concerning their childhood and upbringing, with a focus on their relationships and interactions with their family members and those in their informal and formal networks.

The study participants’ relationships with their parents were, with some exceptions, described as having been close and essential for their upbringing. Most of the parents with ID were perceived to have been supportive of their children growing up with ID. The participants described their relationships with their siblings as important in providing key friendships. The relationships
with relatives, especially grandparents, were likewise seen as having been important; the grandparents engaged in activities with the young children, were supportive of them in a number of ways, and provided them with emotional closeness. Close and sustained contacts with reliable others are, as is well known, important for children’s development, and have been found to be particularly vital for children with ID especially when raised by parents who also have ID (e.g. Cleaver and Nicholson, 2007; Feldman et al., 2002; McConnell and Llewellyn, 2005).

Such resources provided by informal networks could be understood as having helped strengthen the study participants’ power of resistance and increase their resilience. The concept of resilience (Grover, 2005; McMurray et al., 2008; Rutter, 2001) has been offered to explain why children, irrespective of the presence of a variety of psychosocial risk factors in their lives, are able to adopt resourceful strategies that have the effect of ameliorating negative experiences. Such negative experiences related to the upbringing of the participants in this study were, first and foremost, related to their interactions with peers. The experiences of being bullied and harassed by peers had created a feeling of being excluded, a finding documented in previous studies as well (Booth and Booth, 1998; Faureholm, 2006; Gustavsson, 1998). As a result, the young adults participating in this study had few friends or contacts with their peer groups. These negative experiences can be interpreted as reflecting stigmatization, described as situations in which individuals are denied social acceptance (Goffman, 1990 [1963]). Using the concept of stigmatization, which implies a relationship between two parties, the abusive behavior as reported by the participants in the present study could be interpreted as a control strategy aimed at protecting oneself from becoming stigmatized. The behavior, however, could also be interpreted as an willful expression of power (Weber, 1978 [1968]) triggered by a sense of frustration and lack of support to help enable one find other, more socially desirable expressions for one’s autonomy and capability. In this connection, the absence of support from teachers as described by some of the interviewees for this study might then be interpreted as a form of neglect contributing to the development and onset of the violent tendencies.

The interviewee narratives in this study must be read in the light of other studies reporting feelings of aggression, self-injurious behavior, and depression as common among individuals with ID (Cooper and Bailey, 2001; Deb et al., 2001; Gustafsson, 2003). Such findings are in line with the descriptions that the interviewed young adults provided of their tendency for depression and self-destructive behavior such as thoughts of suicide and actual suicide attempts. Individuals in early adulthood with ID have, moreover, in general been found to be at increased risk of attempted suicide in later life as well (Batty et al., 2010).

The stories the study participants presented about support from informal and formal networks during their upbringing provided a stark contrast to such negative experiences, however. The experiences of having a close relationship with one’s own family or a foster family stood out as a bright memory from childhood. Birger’s and Bodil’s stories, for instance, can be understood to imply an understanding that their parents handled the situation in the most constructive possible fashion. The reasons Birger and Bodil provided as to why they had to spend time with a foster family seemed to be quite clear and entirely sensible for them, even at the time they had to leave home as children. That this was so could be interpreted as indicating the possibility that the parents, the foster parents, and the professionals involved had all contributed with information and knowledge that made it possible for Birger and Bodil to create a sense of coherence regarding their environment and upbringing. The support from formal networks could then have served as a way of promoting resilience among these young adults during their childhood. Such a possibility has been considered also by Faureholm (2010), who found that the input of professionals in
combination with support from informal social networks fostered resilience among the young adults included in her own study.

Evidence of such enabling or strengthening processes in the case presented was also provided by the study participants’ reflections about their parents’ role in helping them to become more independent and autonomous. It could be asked, however, whether and to what extent the need for greater resiliency in fact reflected the participants’ and their parents’ desire to become more autonomous in response to their experience of being excessively taken care of by support workers, often based on their identification as non-able persons (cf. Umb-Carlsson and Lindstedt, 2010). Indeed, the adults with ID that Umb-Carlsson and Lindstedt studied frequently stressed the importance of being viewed and treated as an adult, not as a child.

Even though most of the participants in this study described their family life and upbringing in positive terms, there were some whose experience was colored by less than happy memories. Julia’s account of her childhood, for example, could be interpreted as describing a process of ‘parentification’ (Becker et al., 1998). The same experience was also typical among the young women studied by Faureholm (2006). Julia’s case can be interpreted as implying that her parents, the professionals, and/or her relatives remained unable to accurately recognize Julia’s or her parents’ particular needs for support. This would, then, be the opposite kind of experience compared to what Bodil and Birger reported of their parents being well aware of their support needs. Julia’s story can also be interpreted as describing a case of neglect similar to that Johanna had experienced during her childhood. Previous studies (e.g. Tymchuk, 1992) have provided evidence showing that the incidence of neglect can often be attributed to a combination of inadequate parental knowledge about children’s needs, insufficient or unavailable parental education, and lack of support services; too often, the parents do not have the resources, knowledge, skills, proper support, and adequate information to satisfactorily pursue their parenthood and fulfill their children’s needs.

The interviewed young adults, however, had also all been subjected to some form of harassment and bullying during their childhood. Male participants, furthermore, described their experiences of being themselves the offenders in this respect, along with attempts to commit suicide. Both men and women among the interviewees reported experiences of being depressed.

While the exploratory and qualitative nature of this study does not allow for any general conclusions to be made at the present stage, most of the young adults interviewed for this study stressed the importance and general positive influence of their parents and grandparents during their upbringing. The resources provided by the family and the extended family helped strengthen the study participants’ power of resistance and increase their resilience. These strengthening processes should, accordingly, be better acknowledged and drawn upon by professionals in the field. The kind of support that study participants described in this respect is important, given that these young adults also reported experiences of harassment by others, of having themselves been an offender, of attempted suicide, and of significant depression. It seems vital that processes of resilience be better understood and identified for young adults in this population, to better enable them find support systems and overcome processes of exclusion. Furthermore, the participants’ negative experiences of their teachers need to be recognized as indicative of a certain lack of professionalism among the latter. Their experiences could be understood as revealing an issue about attitudes and lack of knowledge, an issue that thus calls for further study in the context of general exclusionary processes impacting this population during childhood.
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