

Expectations of and reactions to disability and normality experienced by parents of children with intellectual disability in Sweden

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Abstract

Background Much research has been devoted to the emotional burdens of having a child with intellectual disability (ID), but very little of this has focused on the burdens imposed by negative public attitudes towards disability. Adjustment has primarily been thought of as adjustment to the actual disability rather than adjustment to attitudes or prejudices towards disability.

Aim The aim of the present study was to study expectations of and reactions to disability and normality experienced by parents of children with ID in their everyday life in Sweden.

Research questions Do the parents relate to the tragedy discourse and, if so, how? Do parents relate to other expectations and disability discourses and, if so, how? What subject positions do the discourses offer?

Method The analysis was based on 17 semi-structured interviews with nine fathers and eight mothers of nine children with different IDs. The children were newly diagnosed and were from 6 months to 5 years of age.

Results Four discourses (tragedy and the lived experience, tragedy and the outsider perspective, the clinical gaze and the super-parent ideal) and subject positions relating to these discourses are discussed.

Discussion The results of this study show that parents of young children with disabilities relate to a wide range of social processes and practices, which could be thought to affect their emotional well-being and parental identity negatively.

Keywords

child, discourse analysis, intellectual disability, parents

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Introduction

The experience of disability is dependant on cultural and social factors, which varies over time and place (Olney & Kim 2001; Reeve 2002; Smith 2005; Goodley & Tregaskis 2006). Expectations of what people with disabilities are and can be and how they should be treated are socially determined perspectives that have great effects on the lives of people with disabilities (Smith 2005) and their families (Green 2007). Most of the research on parents of children with disabilities has been carried out in Anglo-Saxian countries and little is known about the situation of parents in other cultural contexts. The present study was carried out in

Sweden, a country with a developed welfare state and a strong focus on equality between men and women (Gustavsson 1989; Olsson & Hwang 2003, 2006). Swedish parents are, for example, entitled 18 months of paid parental leave per child, highly subsidized child care and a monthly child allowance. Families with children with disabilities get free aids and support from multi-disciplinary teams.

Research on parents of children with disabilities has long been focused on adaptation, defined as adjustment to the actual disability rather than adjustment to attitudes or prejudices towards disability (Olney & Kim 2001). An increased risk of lower level of well-being has been found in mothers (Blacher & Baker 2002;

Singer 2006; Plant & Sanders 2007) but the majority of parents adapt well to raising a child with intellectual disability (ID) (Hassall & Rose 2005; Emerson *et al.* 2006; Olsson & Hwang 2008). Failure to consider contextual factors is likely to reinforce an overly pathological orientation, in which children with ID are assumed to be a 'burden' and a cause of maternal distress when it may actually be the social circumstances that constitutes the risk (Emerson *et al.* 2006). Expectations and prejudices about disability are contextual factors that are often overlooked in analyses of the life situation of parents of children with ID.

Parents often raise their children within the context of a powerful societal discourse that devalues disabilities and they are therefore expected to feel emotionally burdened (Green 2007). Parents with positive attitudes towards raising a child with a disability are sometimes pathologized as being unrealistic, in denial and failing to accept their 'tragic' circumstances (Green 2007). Still very little research has focused on the burdens imposed by negative attitudes towards disability (Green 2007).

The aim of the present study was to study expectations and reactions to disability and normality experienced in everyday life by Swedish mothers and fathers of small children with ID. The concepts presented and discussed in this paper have their roots in literature on disability and identity, and relates primarily to the discourse of 'tragedy'.

Method

Participants

The analysis is based on 17 interviews with nine fathers and eight mothers of nine children with different IDs. The children were newly diagnosed and were between 6 months and 5 years of age. The parents were between 24 and 43 years, with a mean of 31 years. Five parents were on parental leave, six were working, two were studying, two were unemployed and two were on sick leave. All parents lived together with the other biological parent of the child; four children were first children while five children had siblings.

Procedure

Interviews

The parents were recruited through centres providing support to families with children with disabilities, in the southwest of Sweden. The centres mailed information about the study to 'new' families who met the inclusion criteria; the child should

not have been known to the support centres for more than 6 months and the child should have or be under evaluation for a diagnosis of ID and/or autism. The first 10 families who agreed to participate were interviewed. One family dropped out because of time constraints, and one mother did not want to participate in the interview. Ethical approval of the project was not required according to Swedish regulations, but an advisory statement from the National Ethics Committee was requested, and advises were followed.

The parents were interviewed individually at the Department of Psychology in Gothenburg, or at their home. They received a gift certificate equivalent to 10 Euros for their participation. The purpose of the interview was to get a picture of their everyday life situation and was not specifically targeting disability. The interviews were semi-structured (Smith 2003), and focused on four main themes: (1) present life situation (describing an ordinary day; What works well/less well in your everyday life?); (2) changes (Are you trying to change anything in your everyday life? What have you learnt from being a parent to your child?); (3) expectations (How does your present life situation match your expectations?); and (4) the future (What are your expectations and dreams for the future, short and long term?). The interviews lasted 50 to 90 min and were transcribed verbatim in Swedish. All quotations used in this presentation have been examined by a bilingual psychologist to ensure that meaning and nuances were not distorted in the translation to English.

Analysis

The method of analysis used was discourse analysis as described by Willig (2001). The focus was 'What does the text say about the character of the discourse?' The primary interests were: the discourse itself, the different subject positions, and the possibility of acting and experiencing that the different subject positions offer.

The analysis can be described as an oscillation between the interviews and secondary literature. Ideas and formulations could originate from the interview text, in secondary literature or one's own experiences, but all ideas are grounded in the reading and rereading of the interview transcripts. The process can be described as abduction, a combination of induction and deduction.

Results

All of the participants base their narrative on a multitude of discourses. The ones highlighted here are to be regarded as a selection.

The tragedy discourse

According to Watermeyer (2009) and Green (2007), people with disabilities and their families are expected to feel, first and foremost, sad and bereaved. A resistance among people with disabilities to embrace this attribution of loss has been described (Green 2007), as it reduces their personalities to being 'only sad' and define their lives as incomplete. The first discourse found in the present material was named 'lived experience' and described the parents' experience of being a parent of a child with ID in relation to the tragedy discourse. It has been suggested that a key factor for the identity of people with disabilities is that they are drawn to define themselves in opposition to what is expected (Watermeyer 2009). In the stereotypical view of disability, grief is seen as something static (Watermeyer 2009) and the risk is that parents are forced to work towards one binary pole in order to avoid being forced to the other. In the present analysis, three different subject positions were discerned: (i) to relate to the experience of tragedy and grief as something that is not static but changing; (ii) to dismiss the tragedy discourse; and (iii) to confirm the tragedy discourse.

Within the *non-static* subject position, the parent confirmed that there was an initial or ongoing experience of grief but that the feelings fluctuated over time or vanished more and more.

I believe it is a lifelong process. Well, it feels better now, it is something I still live with and I accept and it feels better and better. And that is just how my life situation looks right now.

And then, after having been feeling so bad, and it feels kind of wrong to say that when there are people feeling very bad for a very long time, and this is only half a year ago and I'm feeling great now. And it went kind of quick too for me, to get up on my feet again, even though it didn't feel that way then. But it went quick and smooth.

This subject position gives parents the possibility of acting in a wide range of ways including reflecting on both positive and negative experiences of disability. Reactions and experiences can, for example, be hope, acceptance and confidence as well as sadness and fatigue; the peculiar is that the emotional state is not fixed.

Within the *dismissing the tragedy* subject position, the experience of tragedy or grief is dismissed and the disability is described as having no or limited significance for the parent's life situation. Parents identify with the majority group, emphasize normality and describe themselves as not different from other parents.

Has anything changed since your daughter was born?

Not much, and especially not that she has her chromosome error; we don't care about that. It (the disability) doesn't matter!

I don't think my life with my son will automatically be more difficult because I have a child with a disability compared to anyone else's life with their child. /.../ I don't feel like 'a poor thing'. I don't feel like I have to opt differently because I have a child with a disability. I want to contribute with that, that I don't feel like 'a poor thing'.

This subject position gives parents the possibility of focusing on normality, involvement and mastery. There is a dismissal of the notion that disability should have more negative impact on life than other life events or stressors. Reactions and experiences can, for example, be pride, confidence and sense of belonging, but limit the possibility to acknowledge and reflect on negative experiences if these exist.

Within the *confirmation of the tragedy* subject position, parents confirm experiences of intense or long-term grief or sorrow. There is also identification with the minority (disability) group or a confirmation of feeling different or excluded from the normal life.

I don't know, I just hope that it will be better and better and I hope that eventually I can live for a full week with this, without being sad or crossed and coming up with excuses when people ask about her. But that's not how it feels now.

Well this picture in that paper of the perfect mom and the perfect baby, it could never be me now. I feel excluded, I stand outside, I can never reach that ideal. I can never become the perfect mom and we can never have a perfect family and we will never be normal now, that's how I feel. He changed that.

This subject position is a passive position where parents describe themselves as victims of circumstances but it also gives them a possibility of sharing and reflecting on their negative experiences. Reactions and experiences can, for example, be powerlessness, helplessness and resignation.

The *outsider* discourse involves descriptions of how parents meet, consciously reflect on and are directly affected by the tragedy discourse. Within this discourse, three different subject positions were discerned: (i) others expect tragedy; (ii) the outsider within oneself expected tragedy; and (iii) can outsiders handle the lived experience.

Within the discourse *others expect tragedy*, parents describe how others reduce their experiences to only those congruent with the tragedy discourse and fail to acknowledge other experiences.

The well-baby nurse, she doesn't really fit us. My husband also felt that when he was there with our son, and it was really interesting to hear when he came home. My husband also experienced all those things that I had been thinking about but has not said anything about. It feels like she is not taking us seriously. I mean all worry that doesn't involve his disability, I mean he is actually a kid who can get ill as well, and we've felt that she is not taking that seriously, she's only trying to calm us down all the time with 'Yes it is no big deal that he has Downs and . . .' Good Lord! We're not, I mean crying about that anymore, of course we think about it, but I don't think about that every second that he's got Downs. That's not how it is! But if we go there then she thinks we're crying over that all the time and that that is the only thing we worry about, and that our worry is totally unrealistic. It feels like she thinks that 'No you don't have to worry, it is only because he's got Downs that you worry'. And that's not how it is for us!

This subject position puts parents in a position where their lived experiences are not recognized or confirmed; they are met by others solely from the tragedy discourse. They have to relate to others that expect them to feel something that is not in synchrony with their actual experiences which can make them feel, for example, offended, unnecessarily victimized, angry or sad.

Within the subject position *the outsider within oneself expected tragedy*, parents consciously reflect upon own previous expectations, how they reasoned and viewed disability prior to their own lived experience. Thomas (1999) discusses the incorporation and acceptance of individuals within an oppressed group of the prejudices against them by the dominant society. Internalized oppression relies on internalization of the prejudices and stereotypes held by a non-disabled majority. In the case of parents of children with ID, parents have to relate not only to stereotypes held by the non-disabled majority but also to their own previously held expectations and prejudices against disability. They relate their inside perspective to their expectations and use their knowledge of the outsider's prejudices towards disability to foresee and understand the reaction of others.

I know myself what I have been thinking about these kids. I mean that's the worst, when he came I could feel that I was being punished for all the ugly thoughts that I've had. About how hard it must be to have such a child . . . who sits in a wheel chair, or a child with Downs and such. I mean really, I feel terribly guilty for all those thoughts that I've had.

Do you still feel like that?

Well, not that much any more, I'm enlightened now. Now I feel that I view all disabled kids in a totally different way. I have a whole new view on it and I'm very happy for that. I wish everybody could get that. I mean get to know in a way, know what I've learnt, because I've got a lot of knowledge that I've never would have gained otherwise. / . . . / I have surely said too that I'd rather die, kind of, Good Lord how horrible! And I would do an abortion and you know, I have surely thought so but now I know better, I think. But you can't expect that everybody else know. For them the disabled are alien and they haven't met anybody before and then you're afraid of the unknown.

In this subject position, parents consciously reflect on their preconceptions and expectations about disability and relate these preconceptions to lack of knowledge. Their knowledge and experience have made them see through the prejudices and change their view of themselves and others. Reactions and experiences can be a sense of pride in managing something that they thought difficult, it can also involve a sense of shame of previous thoughts.

Although people with disabilities are expected to grieve, they are at the same time reluctant to articulate their loss, with a pressure to protect others from the real lived, emotional experience. Watermeyer (2009) suggests that it can be difficult to reach self-acceptance and integration of one's own more unpleasant and painful experiences, if these exist, if you are not able to disclose, examine and share these experiences with others. Within the subject position *can outsiders handle the inside perspective*, parents describe how they sometimes feel a need to protect others from the lived or expected experience of disability.

I have learnt that people react very differently, they take things very differently. I have friends that have panicked and 'Oh no! Here he comes, oh!' And that's the worst that it is so very hard for them that he will be sitting in a wheelchair. So I'm taking it more easy now, I don't know, to protect them. Yes, to protect them because I'm so afraid that they should feel bad.

If you call someone that you haven't talked to in a while and they ask 'How's it going?' Should I tell them about everything that has happened? It feels terrible to call your friends and only tell them lots of misery.

Does it feel like you burden them?

I don't know, but it is that feeling, aah, that I have so much misery to tell them about, so many things have been happening that it almost reaches the absurd in a way, and

I have almost not grasped it myself yet, everything that we've been through. And I think about how can I call and offload all this on an unsuspecting human who believes that we live here in total bliss – I find that difficult.

In this subject position, parents take on the responsibility for others' reactions to the tragedy of disability. They feel they need to protect others from the difficult emotions that disability evokes. Reactions and experience can be that others are perceived as fragile, that the lived experience of disability is too threatening to tell about and that others are not able to offer support.

Other discourses

The discourse *the clinical gaze* involves descriptions of situations where parents or their children are being objectified or 'depowered' through the surveillance of experts and others. People in minority groups develop an awareness of how they are seen through the gaze of others and then modify their behaviour via self-surveillance to attempt to make themselves acceptable (Reeve 2002). Within this discourse, two different subject positions were discerned: (i) public stripping and (ii) the cost of claimant.

The subject position *public stripping* refers to situations where parents experienced a position where others (experts or ordinary people) made them or their child feel vulnerable and objectified. A special case is when parents themselves describe the risk of viewing their disabled child in a similar objectified or classified way (e.g. 'that's how children with autism or Downs are') and reflect on their avoidance of doing so.

It was a doctor who made a fool of himself, because the reason I learned about her condition (an uncommon syndrome) was that they took a test on her when she was born and the result came when she was a week old, late in the afternoon, evening. Well, our ordinary doctor went home and then I met our obstetrician at midnight, when I had nursed her . . . and then he told me, in the corridor when I was alone. And then I was to go to bed . . .

You get many comments about your disabled child at the playground. From both kids and grown-ups, well, the kids usually ask their grown-ups and grown-ups can give really stupid answers. / . . . / He lies down on the sand box; he lies down there at the playground driving a tractor or something around, humming and yes – plays . . . And then someone can say, kind of, well, you hear much more than people think, or they say it kind of half laud for you to hear it, but you know they say: 'He is

so tired, he should have gone home, the mom should have taken him home a long time ago, because he's so tired'.

I was afraid at first that we should start treating her as 'the chromosome', instead of as our daughter.

In this subject position, parents (and/or the children) are being defined and treated as 'cases' and not met with empathy or interest in their situation or experience. Reactions and experiences are a feeling of being treated unfair, feeling vulnerable, shame and anger.

The cost to the claimant of accepting disability benefits is often that parents are forced to adopt a negative identity, someone who is abnormal and incapable (Reeve 2002). In contrast to the general support to parents in Sweden, such as the child allowance which comes automatically when a child is born, disability benefits must be claimed based on needs. In order to receive benefits parents need to focus on and report difficulties and shortcomings. The subject position *cost of claimant* refers to depowering experiences in relation to the service delivering arena. Parents describe having to fight for resources, being fobbed off and how success in receiving services relied exclusively on reporting the negative aspects or shortcomings of their child and themselves.

A resource that I have is that I like to write and formulate myself in words, and that is really a full-time job, as when you need to apply for services. People that I know who has much larger need for support than my son gets almost nothing because they have not managed to put down everything, crass, what it is that you do extra. You need to focus and write down all the bad things and it is really hard for some to do that, but I don't feel it is difficult, I can write sadly on a paper and then we get money to do fun things.

In this subject position parents can either stand up and more or less angrily take the fight or give up and get disappointed for not receiving the support they are entitled to. Reactions and experiences include fatigue and disappointment but also pride and determination.

All parents talked about how the child with disabilities meant increased demands for them and the family. They felt a pressing responsibility for giving the child the best prerequisites to develop to their full potential. Most parents struggle to live up to expectations to train their children with ID, but professionals may fail to acknowledge the emotional costs of having to carry out tasks that other parents do not have to do. These tasks, or adaptations of the home, can be seen as reminders of 'abnormality' or simply as too much work. The discourse of *the*

super-parent ideal was the one most often mentioned in the interviews. Within this discourse, two different subject positions were discerned: (i) living up to and (ii) failing.

The subject position of *living up to the super-parent ideal* was associated with the experience of pride and strength in handling the situation. It could refer to the handling of emotional reactions, practical matters and determination of standing up for their child's rights.

I can say that this situation has kind of brought out the best of me, and I can be proud of what I have accomplished, I feel capable.

I think I'm a resource for others with children with disabilities. I, or we, have a website where I write quite detailed about what we do and pictures on all aids we have. And handy handsome tips on toys that are light and fun and how to make a swing so that the child can swing even though he can't sit. How you cast a corset and yes all sorts of things that I would have wanted to find when I found out that he was ill.

This subject position is a position of empowerment, the parent acknowledge the extra demand and gives her/himself credit for standing up to the test. The feeling of success and positive feedback will probably encourage the parent to keep on being active and solution-oriented. Reactions and experiences can be pride, determination and energy.

The subject position of *failing to live up to the super-parent ideal* had to do with the experience of running short. The parent feels he or she fails or runs the risk of failing to live up to their own or other's expectations. Being in need of and getting services can amplify the experience of being different. Services can cause resentment and clarify the conflict between the needs of the child and the needs of the parent.

These experiences often involve feelings of guilt, shame or frustration.

Well I feel more or less bad every night when I go to bed. It is always something that you have not had time to do of all those things that you're supposed to do.

But it is still, hell, not again, one meeting a week, it is kind of hard to have people around the house all the time and they tell you what kind of light you should have at home and everything because it is good for her sight, and it is a pain in the ass! I find it incredible hard to live with that, it is not only the three of us but it is goddamn it all kind of people involved. I don't even know who's who anymore! I mean it is the special teacher, the sight

woman, the physiotherapist, the OT and so many and everybody does their thing and they kind of come and tell us how we're supposed to have it around our house, what's good for her. But nobody ever sees that . . . oh no, it isn't working, I can do some changes but I'm supposed to feel comfortable here as well. I don't want to turn my home into a disability centre.

In this subject position parents experience inadequacy; their resources are not sufficient to live up to the super-parent ideal of helping their child and putting their child's need first. Reactions and experiences are shame, feeling overburdened and stressed.

Discussion

The results of this study show that parents of young children with disabilities relate to social processes and practices, which may affect their emotional well-being and parental identity negatively in concordance with what Goodley and Tregaskis (2006) found. Parents of children with disabilities, like people who acquire their disabilities during the course of life, have access to an outsider perspective on disability and prejudices, a knowledge that they use to guide their expectations of others' reactions. The knowledge can be seen as a resource as it can be used to foresee reactions, and place own reactions in relation to anticipations of more negative reactions. But the previous expectations and thoughts may also be something that the parent is ashamed of and something that makes them overly suspicious and worried about the reactions of others. Either way, preconceptions were something that parents actively related to and struggled to come to terms with.

The tragedy discourse was prominent in the material, and three different positions with different impact on identity were found. Describing the lived experience as not static seem to be close to the ideal that Watermeyer (2009) suggest. In this position, the experience of disability is blended in with other life experiences in balanced and dynamic ways, and the emotions evoked fluctuate over time. In dismissing the tragedy discourse position, parents define themselves in opposition to what is expected, as strong and not bereaved, but with the risk of suppressing other subjective experiences. By focusing on normality, the possibility of finding affinity within the disability subgroup may be less likely. Should a dismissal of the tragedy discourse be seen as denial and the result of a pathological resistance to accept the disability? No, Goodley and Tregaskis (2006) suggest that a fully representative and inclusive approach to understanding and managing the effects of disability is required to provide families with the holistic understanding and support

they need. Confirming the tragedy discourse gives parents a possibility to process and share their experience with others, especially if they get involved with other parents of children with disabilities. A lingering in this position may, however, become a self-fulfilling prophecy as the position is also a passive one where parents view themselves as victims of circumstance. Apart from the fact that parents in this position seem to suffer the most, it also raises the question about the value of life. Is it the lack of value of the child's life that is mourned or is it the parent's life with their child that is lacking value (Goodley & Tregaskis 2006)? In order to increase parents' quality of life, this question needs to be addressed.

Within the outsider tragedy discourse we found that even people who work professionally with parents of children with ID sometimes reduced, filtered or turned parents' narratives to be compatible with the tragedy discourse. This is in line with what Watermeyer (2009) called being reduced to being 'only sad' and the child's humanity is being reduced to his or her impairment (Goodley & Tregaskis 2006). The paradox within the tragedy discourse, the pressure to protect others from the real lived experience was also described by parents. The protection of others may result in lost support from both the informal and formal support network.

The other discourses described can be seen as having something to do with power and surveillance either by others or by self-surveillance (Thomas 1999). The child's disability placed the parents in an underprivileged position involving situations where parents of children with ID were seen as a group that experts and others felt free to monitor and comment on without taking context or subjective experiences into consideration. The child and the parent deserve being viewed as holistic human beings, but this requires professionals and others to admit complexity and avoid oversimplified label use (Goodley & Tregaskis 2006). In concordance with other studies (e.g. Olsson & Hwang 2003; Goodley & Tregaskis 2006), many parents had experiences of having to struggle to get access to supporting resources controlled by others. The process of getting support in Sweden involves a depowering experience of having to focus on shortcomings and difficulties in relation to the disability. Parents further expressed a fear that they extended the clinical gaze by objectifying their child, that is, that the child's personality and identity as a family member became secondary to the diagnosis and disability.

Parents in Sweden today raise their children in a growing knowledge society with high parenting expectations. Parents of children with disabilities face a myriad of information and advice connected with bringing up their kids with special needs (Goodley & Tregaskis 2006), a knowledge gain that may not be

entirely good, as it raises the pressure on parents. As described within the super-parent ideal, parents had incorporated the view that parents of children with ID needed to be extraordinary in order to give the child the best possible conditions for development. Parents used self-surveillance to evaluate themselves as parents and judge if they lived up to the ideal or not. This ongoing evaluation sometimes resulted in pride and determination but more often in stress, sense of guilt or failure in parents.

This study has focused on how mothers and fathers of children with ID in Sweden relate to the concepts of disability and normality when they describe their everyday life as a parent. The results could be seen as evidence that parents of children with ID experience and have to relate to discourses and prejudices, which can have negative effect on their well-being. The discourses described in this study should not be seen as universal, extensive or stable but rather as examples of what parents can meet in relation to others and themselves. The study is limited in number of participants and cultural context and no comparative approach is possible. We do not intend to explain individual or group differences in experiences but rather look at all the narratives as an entity. This study has the strength of presenting data from a Swedish cultural context and involves responses from both mothers and fathers. In future studies, it would be valuable to relate the experience of different subject positions to parents' well-being and personality characteristics.

Key messages

- Parents of children with ID experience and have to relate to discourses and prejudices such as the tragedy discourse, which can have negative effect on their well-being.
- Families with children with disabilities are often seen as victims, which can make them prone to disprove this view.
- Parents used self-surveillance to evaluate themselves as parents and judge whether they lived up to the ideal or not. This ongoing evaluation sometimes resulted in pride and determination but often in stress, sense of guilt or failure in parents.

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