

# Parenthood and Intellectual Disability: Discourses on Birth Control and Parents with Intellectual Disabilities 1967–2003

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**ABSTRACT** *In 1975, the sterilization of persons with intellectual disabilities was anned in Sweden. The ban can be regarded as an expression of a changed attitude towards persons with intellectual disabilities and towards their right to equal living conditions during the latter part of the 20th century. The question addressed in this study is whether this shift was paralleled by a changed discourse on intellectual disability and parenthood. I will argue that childbearing and parenthood in relation to individuals with intellectual disabilities have continued to be described as problematic and, therefore, as best avoided. The changed discourse on the rights of intellectually disabled persons, however, made it discursively impossible to suggest a coercive application of birth control methods. Instead, birth control was now introduced as an option and a benefit for the woman.*

In late August 1997, Sweden and the Swedish welfare state were in the headlines of major newspapers around the world. The reason was the revelations presented in an article by journalist Maciej Zaremba (1997) in *Dagens Nyheter* about the Swedish sterilization policy during and after World War II. (However, in research on the Swedish welfare state, the sterilization policies of the inter- to post-war years had long been known (Broberg & Tydén 1991, 1996). The reaction to these revelations in the Swedish media was fierce, and journalists excelled in condemning what was regarded as a shameful segment of Swedish history. Two years later, a law was passed to satisfy the claims for indemnification made by the individuals concerned (SFS 1999:332). The indignant reaction of the public as well as the wish to condemn the sterilization policy of the inter- to post-war years is understandable. However, this indignation was not extended to, and perhaps even stood in the way of, a critique of how the issue of intellectual disability and parenthood is handled today. Instead, by dissociating ourselves from the assaults of the past, we also effectively position our own age in contrast to the practices of the past. “Welfare stopped the sterilizations” was one of

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the headlines in a major Swedish daily newspaper (Lindqvist 1997). This may very well be part of the explanation, but the question that should be asked is: did welfare change the way we view and describe childbearing and parenthood in relation to persons with intellectual disabilities?

The overall aim of this study was to investigate whether the Swedish discourse on intellectual disability and parenthood changed during the latter part of the 20th century, and if so, how. The questions posed and answered in this article are whether and in what way intellectually disabled parents have been described as a problem during the period from the late 1960s until now, what possible solutions were suggested and how they were worded (Edelman 1988, Haldén 1997). The last section of this article comprises an analysis of how the issue was dealt with in the media at two specific points in time.

The issue of intellectual disability and parenthood concerns actual as well as potential parenthood. Thus, it concerns intellectually disabled parents as well as the possibility of persons with intellectual disabilities becoming parents. As such, the issue is characterized by a dilemma regarding the relationship between the right of the intellectually disabled person to integrity and self-determination and the obligation of the state to protect citizens who are defined as weak. Belonging to the social categories traditionally regarded as weak, and therefore in need of societal protection, are persons with intellectual disabilities as well as children. The issue of intellectual disability and parenthood thus harbours two potential conflicts: (i) between the right of intellectually disabled parents to integrity and children's right to protection; and (ii) between the right of individuals with intellectual disabilities to self-determination and a normal adult life, on the one hand, and their right to societal protection and support regarding issues and decisions with which they may need assistance, on the other.

### **Discourse Analysis**

One of the premises of the analysis presented here is that we can investigate social change by analysing changes in language. Language is presumed to reflect as well as to, at least to some extent, construe social change. Depending on the words used to refer to or describe certain phenomena, categories or groups of individuals, textual expressions can mould and possibly change our ideas of and attitudes towards these phenomena. However, the causal effect of textual expressions or discourse on social change is both limited and uncertain. Language is not the only factor of social life that can produce change, and the effects of discursive change are determined by several contextual factors, such as economic and political factors. However, there is still reason to investigate discursive changes in various textual expressions, as they both reflect what could be expressed during different periods of time and constitute, in part, the changes that our images of and attitudes towards a certain phenomenon have undergone (Fairclough 2003).

Discourse, in this article, refers to a system of rules that allows and legitimizes certain textual expressions rather than others. The question addressed here is how the issue of intellectual disability and parenthood has been handled in official recommendations published by governmental authorities such as the Swedish National Agency for Education (Skolverstyrelsen/Skolverket) and the National Board of Health and Welfare (Socialstyrelsen), in parliamentary reports, in specialist literature and in articles published in one professional journal from the 1960s to the 1990s. The journal in question is *Psykisk Utvecklingshämning* (1962–87, later *PU-Bladet* 1988–92) published by the Nordiska Förbundet Psykisk Utvecklingshämning (The Nordic Association of Mental Retardation) with editors from Finland, Denmark, Norway and Sweden. The journal, according to its own statement on publication areas, published articles on prevention, diagnostics, education and care of the mentally retarded.

The publications providing the empirical data for the present analysis are, thus, of various kinds. The documents published by the two authorities constitute official positions and recommendations concerning how the issue of intellectual disability and parenthood should be dealt with in, for example, care and welfare services. The journal *Psykisk Utvecklingshämning* instead constitutes a Nordic forum for presentation of research results without necessarily stating a line of action. There are, however, obvious connections between these different types of publications. The publications of the National Board of Health and Welfare, for example, often referred to results of scientific investigations published in journals such as *Psykisk Utvecklingshämning*. Furthermore, Karl Grunewald, who among other things wrote the preface to one of the booklets on intellectual disability and parenthood published by the National Board of Health and Welfare, was the chief editor and publisher of *Psykisk Utvecklingshämning* during the period 1962–87.

In addition to the publications mentioned above, the study was planned so as to include another journal: the periodical of the Swedish parent organization Riksförbundet för Utvecklingsstörda Barn Ungdomar och Vuxna – FUB (The National Association for Mentally Disabled Children, Youth and Adults) *FUB-Kontakt*, which was first published in 1966. The articles published in *FUB-Kontakt* were intended to represent a voice partly different from the voice of scientific articles in *Psykisk Utvecklingshämning* or the official recommendations of the National Board of Health and Welfare. However, intellectually disabled parents and birth control turned out to be an issue touched upon in very few articles in the FUB periodicals. Several articles dealt with sexuality, but the issue of parenthood was left aside. The policy of the organization on this question was in line with its policy in general: persons with intellectual disabilities have the same rights to sexual experiences as everybody else. Therefore it is noteworthy that the recognition of their rights did not include the question of parenthood.

The reports, recommendations and journal articles that are the empirical data constitute a political/scientific discourse. The rules that regulate a political or state discourse are not necessarily the same as those that guide a

scientific discourse. Regarding the issue of intellectual disability and parenthood, however, they have proved difficult to separate with regard to content as well as agents. Discourse analysis as a theory and research method generally does not focus on individual agents (Bergström & Boréus 2000). The main focus of Foucault-inspired discourse analyses, in particular, tends to be structural power rather than the role of the individual in the constitution, maintenance and change of discursive structures. Other discourse theorists, such as Norman Fairclough, have instead tried to scrutinize the significance of social structures as well as that of social agents in text production. Fairclough does not describe individuals as free agents, but as socially constrained in their scope of action. However, this does not make their actions socially predetermined. Thus, because factors other than social structures influence the actions of individual agents, the wording of a text cannot be explained solely with reference to social structures (Fairclough 2003).

The following analysis begins with a short account of the so-called normalization principle that came to characterize discourses of care and services for the intellectually disabled from the late 1960s and an analysis of its effect on attitudes towards intellectual disability and sexuality as they were expressed in the publications constituting the empirical data for this study. Next follows an analysis of the ways in which parenthood in relation to intellectual disability has been described as a potential problem and the measures that have been suggested as solutions, that is, birth control and control of the parents. The analysis ends with a discussion about the relationship between the rights of children, parents and the intellectually disabled, using media coverage of the question at two different points in time as a starting point.

### **Normalization and Sexuality**

At the end of the 1960s, Bengt Nirje put into words the so-called normalization principle, according to which individuals with intellectual disabilities were entitled to the same living conditions as the population in general (Nirje 1969). One of the claims of the normalization principle was that intellectually disabled persons were entitled to non-institutional housing, which would increase their opportunities to have social contacts, encounters with members of the opposite sex, relationships and a sexual life. The opportunity to develop, satisfy and find pleasure in one's sexuality was now described as a right for adults with intellectual disabilities (see, e.g., Katz 1975).

Enabling the intellectually disabled to have sexual experiences, however, was not solely a matter of rights. An account of sexuality as deeply biologically rooted also represented the opportunity for sexual expression as necessary for preventing the negative effects of suppressed sexuality on an individual's development and behaviour (Lydecken 1967, Grunewald 1972). The sexuality of adults with intellectual disabilities was described, thus, as natural – something that ought to be a natural part of their lives. At the same time, however, it was represented as something potentially problematic.

Suppressed sexuality was claimed to cause infantile, egocentric, anxious or insecure social behaviour and to sometimes leave intellectually disabled individuals “sexually charged” (Grunewald 1972:45). Another potential problem ascribed to the sexuality of adults with intellectual disabilities was the risk that it would find expressions that were not socially accepted in society. Therefore, sexual education specially designed for the intellectually disabled was claimed to be important. In the *Handledning och studieplan i sexualundervisning i särskolan (Guide and syllabus for sexual education in special schools)* published by the National Agency for Education in 1967, the aim of sexual instruction was described as threefold: students should be able to have pleasure in sexual life as adults, they should learn the cultural norms for life in a relationship and they should gain enough knowledge to be able to protect themselves against abuse. One aim of conveying norms to students in sexual instruction was to warn about behaviours that were perceived as inappropriate because they could result in situations that were difficult for the individual to master. Another aim was to:

protect the students from developing behaviours that might be regarded as importunate and therefore could cause them adversities and render their social contacts more difficult. (Wessman 1968:15)

It was emphasized, however, that the teacher should not moralize or repudiate behaviours that were not in accordance with what was perceived as desirable. Similar recommendations – that is to convey norms without taking a moralizing stance – also applied to information concerning the body and masturbation. Students were to be imbued with a relaxed attitude towards their genitals, but at the same time learn to be reserved about exposing them (Wessman 1968).

In the National Board of Health and Welfare publication *Samlevnads- och sexualfrågor hos psykiskt utvecklingsstörda (Relational and sexual matters among the mentally disabled)* from 1975, the purpose of sexual information was expressed in a similar way. It should teach intellectually disabled persons to keep a certain distance, to show respect for other people’s private sphere and “a normal diffidence”. Sexual instruction should therefore include information on appropriate words for speaking about sexuality as well as advice on how to seek privacy for masturbation (Katz 1975, see also SOU 1981:26). Hence, equipping students with norms to live by without generalizing or judging other ways of life was described as one of the major challenges for sexual education.

The importance of conveying sexual norms to adolescents with intellectual disabilities was also discussed at two conferences organized by Nordiska Förbundet Psykisk Utvecklingshämning (The Nordic Association of Mental Retardation) under the title “Sex – en del av livet” (Sex – a part of life) in 1988 and 1989. At the conference, the principal of a Danish special school, Jørgen Buttenschøn, argued that the increased participation of the intellectually disabled in society required that they learn to live in accordance with the same rules and norms as everybody else (Buttenschøn 1990). The importance of learning socially acceptable sexual behaviour was also

emphasized by Norwegian specialist practitioner Roy Nystad and psychologist Katryn Olsen. They claimed that lack of knowledge and social skills could result in a variety of problematic behaviours, such as young girls feeling pressured to have sexual relations at work, public exposure of genitals, masturbation in the bathroom, indiscriminate sexual behaviour, promiscuity, etc. (Staude 1990). Thus, the potential roles as victim and as offender were described as equally problematic.

Many of the recommendations for sexual instruction in special education emphasized the importance of conveying to the students behavioural norms that corresponded to those of the non-disabled majority. The need for information was motivated by the claim that knowledge about societal norms would facilitate the social contacts of adolescents with intellectual disabilities. One consequence of the fact that sexuality became an accepted and even encouraged part of their lives was that the issue of childbearing and parenthood received renewed interest.

### **Unwanted Parenthood**

While sexuality and sexual relations involving persons with intellectual disabilities were increasingly described as acceptable and accepted after the late 1960s, parenthood continued to be pointed out as controversial (Johansson & Wrenne 1981, Liljeqvist 1984). In the instructions for sexual education in special schools published by the National Agency for Education in 1967, childbearing and parenthood in people with intellectual disabilities was presented as a source of problems. Therefore, education in contraceptive techniques and a liberal attitude towards abortion were described as necessary to “avoid personal tragedies” (Wessman 1968). One example of the representation of parents with intellectual disabilities as a potential problem is the following quotation from a National Board of Health and Welfare publication from 1975 about how the life situation of an intellectually disabled woman would develop if she became pregnant.

The situation often becomes difficult for a mentally disabled woman when she expects a child, regardless of whether or not she is married. An abortion might be advisable. (Katz 1975:36)

Equally explicit was the standpoint that individuals with intellectual disabilities should not become parents. This opinion was especially apparent in relation to views on marriage and sexual relations as such.

The fact that a mentally disabled person ought to refrain from having children should not be confused with whether one can have a sexual relationship or not, whether one can marry or not! (Katz 1975:25)

Hence, the recommendation issued was that individuals with intellectual disabilities should be made to refrain from having children. “One should advise mentally disabled persons against parenthood” was also the essential recommendation of the National Board of Health and Welfare, as it was

issued in *Utvecklingsstörda och föräldraskap* (The Mentally Disabled and Parenthood 1980:3).

According to Margareta Nordeman, the issue of intellectual disability and parenthood continued to be viewed as a very controversial matter during the 1990s, and persons with intellectual disabilities were continuously advised against having children (Nordeman 1999). According to a publication from the National Board of Health and Welfare published in 1990, there was:

great agreement in the care sector that individuals in need of substantial special care ought not to be parents out of consideration for the children as well as themselves. (*SöS-rapport* 1990:8. See also p. 25)

What distinguishes the 1990 quotation from the two previous quotations is that the disapproval of individuals with intellectual disabilities becoming parents was not presented as a recommendation or direction, but rather as a description of the prevailing attitude towards this matter in care and service organizations. Instead of expressing the standpoint of the National Board of Health and Welfare, as in the previous publications, the alleged agreement on the unfitness of persons with intellectual disabilities as parents was used as a way of conveying the authority's message.

The 1990 quotation also differs from the two previous quotations in the way in which it defines the group of individuals who ought to be advised against becoming parents. While the publications from 1975 and 1980 spoke of "mentally disabled" (*utvecklingsstörda*), the quotation from 1990 referred to "those who are in need of substantial special care" (*de som är i behov av omfattande särskilda omsorger*). In this way, the advice against parenthood was linked to the need for assistance rather than to the intellectual disability itself. The pronounced recommendations to advise persons with intellectual disabilities against parenthood constitute a boundary for normalization efforts regarding the opportunities and living conditions of the intellectually disabled. While their sexuality was to be encouraged, parenthood was treated as something to be avoided. Hence, the question for the following section is how the possibilities to control childbirth in individuals with intellectual disabilities were described after the late 1960s.

### **Birth Control**

The normalization principle and the subsequent individualization of care and services for the intellectually disabled created a new image of persons with intellectual disabilities towards the end of the 20th century. Using coercive means to prevent people from becoming parents was no longer viewed as acceptable. At the same time, however, as has been shown above, intellectually disabled parents continued to be regarded as potentially problematic.

During the inter- to post-war years, the image of persons with intellectual disabilities was different, and the issue of their parenthood was met with sterilization laws (SFS 1934:17, 1941:282). Two of the arguments used for the sterilization policy of this period were to prevent the transmission of hereditary dispositions for feeble-mindedness to future generations and to

prevent individuals who were regarded incapable of taking care of a child from becoming parents. (For a detailed discussion on Swedish sterilization policy see, e.g., Runcis 1998 and Tydén 2002.). The application of the sterilization laws gradually changed, and the number of feeble-minded in relation to the total number of sterilized decreased, and in 1975 the legislation was changed. Since then, sterilizing operations may be performed only on the request of the patient her-/himself, which implies that individuals who are judged to lack the intellectual capacity to make such a decision may not be sterilized (SFS 1975:580). In practice, this means that it is illegal to sterilize a large proportion of persons with intellectual disabilities.

One determining factor for the change in application of the legislation and subsequently its abolition was, of course, the introduction of new contraceptives during the 1960s (the pill in 1964 and the intrauterine device (IUD) in 1966). However, the opinion at that time was that these contraceptives were rather difficult for intellectually disabled women to use. According to Mattias Tydén, the difficulties of achieving effective birth control with the aid of contraceptives that were used and thus controlled by the individual herself may have led to a situation in which “less radical contraceptive techniques . . . have been and perhaps still are forced on those individuals who are now referred to as intellectually disabled” (Tydén, 2000:453–454). Officially, however, the use of coercion with regard to birth control is no longer acceptable. An interesting question, therefore, is how the acceptable modes of procedure for birth control for the intellectually disabled have been worded and launched during the latter part of the 20th century.

The recommendations of the National Board of Health and Welfare regarding birth control for the intellectually disabled from 1980 illustrate how the dividing line between acceptable and unacceptable means was worded.

The fundamental principle in guidance on contraceptives is the issue of motivation. One may not force, command, persuade or coax people to use contraceptives. What you may do is help them find reasons to protect themselves. (*Utvecklingsstörda och föräldraskap* 1980:14–15)

By describing the value of birth control as something that persons with intellectual disabilities ought to receive assistance in comprehending, birth control as such was represented as a benefit – something of use to the individual. Furthermore, the word “help” signals differentiation from such modes of procedure as to “force, command, persuade or coax” somebody to use contraceptives.

In the National Board of Health and Welfare information booklet *Föräldrar med nedsatt begåvning och deras barn* (*SoS-rapport* 1990) (*Parents with impaired intellectual abilities and their children.*), the word “support” (*stöd*) has a similar effect. Although it was claimed that individuals with moderate functional impairments were known from experience to practically never parent a child, some of them were still said to “receive support in using contraceptives” (p. 7). Furthermore, in cases where a pregnancy had been revealed, it was recommended that “the woman should receive support in deciding whether she wants to give birth to the child or have an abortion” (p. 24).

The question of giving support to women with intellectual disabilities in decisions concerning abortions was worded in a similar way in an article published in *Psyisk Utvecklingshämning* in 1984. If the social situation of the woman was such that a child would thwart her future possibilities to cope, the author claimed it was important that the woman "...be given the opportunity to carefully consider the question of abortion together with staff on the local habilitation board" (Liljeqvist, 1984:26).

"Considering the question of abortion" was described as an opportunity (*möjlighet*) for the woman, and the abortion was thus justified out of consideration for the woman and her future. The same choice of words, however, in relation to the use of contraceptives can also be found in an article published in *Läkartidningen (The Physician Journal)* in 2003 about the causes of the dramatic decrease in the number of women with intellectual disabilities who gave birth. The main explanation for this change was sought in "...the increased psychosocial support these women had received and the opportunity of controlled childbearing" (Bager 2003:24).

Avoiding pregnancy and childbirth with the aid of birth control and abortion was thus described as an opportunity for the individual and not something that was forced upon her.

Giving somebody help, support or the opportunity to make a decision implies that the person herself participates in the decision-making. Consequently, it was described as desirable that the intellectually disabled person herself realized that it was for the best if she did not have a child. The prerequisite for such an understanding was claimed to be her realization of her own limitations or what was called handicap awareness (*handikappmedvetande*). In turn, such self-knowledge was said to require that the person accept her shortcomings, whereby some "negative and painful consequences" of the handicap were claimed to be inescapable (*Utvecklingsstörda och föräldraskap* 1980:14. See also Johansson & Wrenne 1981). The kind of realization the individual was claimed to gain from handicap awareness was said to protect her from getting into situations that would lead to further failures and disappointments (Liljeqvist 1984). The overall goal, as it was defined here, was for the individual to gain a realistic and positive self-image and for her handicap awareness to promote self-confidence.

The challenge for the people closest to adolescents with intellectual disabilities was argued to be making them realize and accept their shortcomings – and at the same time helping them gain a positive self-image.

How shall we manage to help mildly mentally disabled adolescents gain such a positive handicap awareness, such a realistic perception of themselves that those of them who could not cope with caring for and bringing up a child voluntarily refrain from having a child? (Liljeqvist 1984:20. See also *SoS-rapport* 1990 and Nordeman 1999)

Self-awareness and self-confidence were not only supposed to help the intellectually disabled woman realize that it would be difficult to take care of a child, they would also help her find self-worth that was not linked to motherhood. With solid self-esteem, she would be better prepared to withstand what was referred to as a one-sided account of happy adult life,

as it was displayed in weekly magazines, and would spontaneously refrain from becoming a parent (Katz 1975, SOU 1981:26). By emphasizing the need for intellectually disabled women to be able to resist the images of weekly magazines, it was implied that many of these women let themselves be duped into believing that having a child was the only way to a happy adult life. The discursive effect of this is twofold. The image of parenthood as a necessary part of adult life is presented as a myth, rendering the request for intellectually disabled individuals to refrain from parenthood less severe. Furthermore, the wish of intellectually disabled women to have a child was portrayed as a desire based on false notions of the happy adult life.

Many women with intellectual disabilities were said to wish for a child for what were described as the wrong reasons, that is, the expectation that a child would improve the woman's status and offer her acknowledgement from those around her (Johansson & Wrenne 1981). In the National Board of Health and Welfare information booklet from 1980, it was described as "... particularly unfortunate when mentally disabled individuals believe that a child can remove the label of mental disability" (*Utvecklingsstörda och föräldraskap* 1980:14).

For these women, parenthood was claimed to be about gaining a sense of self-worth by making the scope of their own helplessness appear less significant in relation to that of a child.

A child may be just the kind of proof of ability, competence, normality and adulthood they believe themselves to be in need of. (*Utvecklingsstörda och föräldraskap* 1980:10. See also Liljeqvist 1984)

The explanations for why intellectually disabled women wish for a child were, thus, mainly sought in what was described as various kinds of fallacies and delusions, i.e. an unrealistic notion of what it is like to take care of a child, the idea that a happy adult life must include parenthood and the thought that a child would make her own need for assistance seem less significant.

Birth control in 21st century Sweden has to be voluntary. For several decades, it has been impossible to suggest that anybody should be forced to use contraceptives. What has been possible, however, is to claim the right of individuals with intellectual disabilities to receive assistance and support in their decisions regarding birth control. The individual's realization of her inability to take care of a child and of the way her life situation would be complicated by the birth of a child, thus, constituted the discursive basis for claims made about birth control in relation to the intellectually disabled. Handicap awareness and an acceptance of one's own limitations were described as a pre-requisite for such a realization. Such self-awareness was, as we will see in the next section, also defined as a pre-requisite for efforts to help those who still chose to become parents, to succeed.

### **Parent Control**

In the National Board of Health and Welfare information booklet from 1980, two different kinds of preventive measures were discussed: to "prevent a

mentally disabled woman from having a child she lacks the ability to take good care of” and to “prevent children from being harmed” (*Utvecklingsstörda och föräldraskap* 1980:38). The issue of intellectual disability and parenthood is, thus, not only about preventing parenthood. It is also about the question of how parents with intellectual disabilities should be treated. While contraceptives and abortions were mainly motivated out of consideration for the intellectually disabled woman, the question of how intellectually disabled parents should be treated centred principally on the well-being of the child.

The legislation concerning care and service for individuals with intellectual disabilities says nothing in particular about support related to parenthood. The National Board of Health and Welfare did suggest, however, that expectant mothers with intellectual disabilities should be given comprehensive and practical information at prenatal and children’s clinics. The clinics, in turn, were said to require information on intellectually disabled parents in general as well as on individual mothers and their children (*Utvecklingsstörda och föräldraskap* 1980:17, 20. See also *SoS-rapport* 1990:17). The need for exchanging information on the intellectual disability of an expectant mother was also addressed in an article in *Psykisk Utvecklingshämning*. According to the suggestion in this article, pregnant intellectually disabled women should be introduced at the prenatal clinic by a habilitation counsellor or psychologist, as the midwife may otherwise remain unaware of the intellectual disability. Furthermore, it was suggested that the information on every newborn child (that in Sweden is automatically sent from the maternity hospital to the children’s clinic) be supplemented with detailed verbal information regarding the intellectually disabled woman and her child (Liljeqvist 1984). This exchange of information between different public agencies was also recommended in The National Board of Health and Welfare information booklet from 1990. In cases where the woman did not voluntarily make contact with social services, the care staff was ascribed the obligation to report her, which was warranted by the aim to assist the family as promptly as possible (*SoS-rapport* 1990).

In 1980, the Nordiska Förbundet Psykisk Utvecklingshämning (The Nordic Association of Mental Retardation) in collaboration with the Swedish Board of Health and Welfare arranged a symposium on the topic “The mentally disabled as parents”. It was emphasized that the intellectual disability of a parent should not generally be regarded as a reason for taking a child into custody, but that intellectually disabled parents should be viewed as a risk category in need of considerable support (Östh 1980). Such assistance, it was emphasized, should be provided with respect for the integrity of the parents and should be experienced by the parents as support and not as questioning of their abilities (*Utvecklingsstörda och föräldraskap* 1980, SOU 1981:26, Liljeqvist 1984). At the same time, it was claimed to be unacceptable if parents declined all contact with responsible care and service units. Losing contact with, and thereby control over, an intellectually disabled couple who were expecting a child was described as a most threatening scenario (Östh 1980, Liljeqvist 1984). In the information booklet provided by

the National Board of Health and Welfare from 1980 as well as in the report of the committee on care of the mentally retarded from 1981, it was admitted that the measures regarding intellectually disabled parents did indeed aim at supporting as well as controlling them. The problem, as it was described here, was that the experience of control had become predominant, which had caused some parents to withdraw from all contact with authorities (*Utvecklingsstörda och föräldraskap* 1980, SOU 1981). One example of how the fear of this scenario found expression is the assertion that there were intellectually disabled women who, out of fear of being persuaded to have an abortion, abstained from visiting a prenatal clinic (Liljeqvist 1984). In the National Board of Health and Welfare recommendations from 1990, it was even claimed to be the rule rather than an exception that intellectually disabled women were anxious to keep their pregnancy a secret (*SoS-rapport* 1990).

Another line of argument suggesting that intellectually disabled parents who withdrew from the assistance and supervision provided by social services were regarded as threatening is the claim that individuals with intellectual disabilities were often able to conceal their difficulties by giving the impression that they understood more than they did. This, too, was said to illustrate the importance of convincing parents that the assistance offered was not a matter of surveillance. Failure to convince them was claimed to create "a great risk that the parents would try to present a false image of themselves as competent" (*SoS-rapport* 1990:22,18).

According to the 1981 report of the committee on care of the mentally retarded, all execution of care in relation to parents with intellectual disabilities should not only support the parents, but also supervise the development of the child and see to the interest of the child (SOU 1981:26). The latter duty, seeing to the interest and rights of the child, touched upon the question of what would happen in cases where all measures of assistance and support were evaluated as futile. In these cases, the National Board of Health and Welfare prescribed an investigation of what would be best for the child. With reference to *the Children and Young Persons Act*, the Board also emphasized the legal authority of society to take into custody children whose development was being jeopardized by poor conditions of living and care (*Utvecklingsstörda och föräldraskap* 1980). However, taking children into custody was described as a measure to be used only when other measures had failed and only after the reason for this measure had been thoroughly explained to the parents, who should ideally also have the opportunity to participate in the placement of their child in a foster home (SOU 1981:26).

Intellectually disabled parents were described, thus, as a risk category. This was argued to warrant the provision of special support and assistance. The assistance, however, was described as an offer that parents could not refuse, and part of its aim was to maintain a certain degree of supervision of the parents. The status of intellectually disabled mothers as a risk category was also claimed to warrant the exchange of information about her case between the various public services she came in contact with during and after her pregnancy. Although it was emphasized that parents with intellectual

disabilities should not be judged beforehand, they were at the same time expected to accept supervision and identified as requiring assistance.

### **Rights of Children, Parents and Persons with Intellectual Disabilities**

The underlying argument for support and surveillance of parents with intellectual disabilities was society's concern for the best interests of the child. The question of how intellectually disabled parents should be treated thus harbours a potential conflict between the parents' right to integrity and the child's right to protection against an unfavourable upbringing. In a sense, such a conflict characterizes all situations in which a child is found to be faring badly in its parental home and taking the child into custody is being considered. Regarding parents with intellectual disabilities, however, the potential conflict concerns an additional aspect: the right of individuals with intellectual disabilities to self-determination and to the same treatment as other adults. In the following text, I will investigate how the wording of this conflict was used as a discursive strategy in asserting two different positions regarding intellectual disability and parenthood in articles published in the journal *Psykisk Utvecklingshämning*, in parliamentary bills and in daily and evening papers at two points in time: the early 1980s and the early 2000s.

At the beginning of 1980, the issue of intellectually disabled parents was debated in the media. In an article in *Dagens Nyheter* (Sweden's largest morning paper), the social welfare officer Anitha Rönström claimed in an interview that far too much consideration had been given to the handicap of intellectually disabled parents when the living conditions of their children were assessed. As a result, taking children into custody had been delayed in several cases. Rönström's opinion was that none of the available support measures – such as an individual contact person, support families, home help and daycare centres – was sufficient to provide a normal developmental context for the child. She claimed the situation could never be good for the child and concluded by posing a question:

Is it so important to satisfy these parents' need to have a child that we are willing to sacrifice the children? (Jöberger 1980)

Hence, Rönström put the best interest of the child in a discursive state of opposition to the needs and wishes of the parents. When Rönström's claims were addressed in an article by Karl Grunewald a few days later, he maintained the standpoint of the National Board of Health and Welfare that an intellectually disabled couple must be assisted in their decision-making regarding the pregnancy through the provision of information on how challenging parenthood can be. Individuals with intellectual disabilities, who still chose to become parents, should receive support and assistance (Grunewald 1980). Grunewald, however, did not comment on the conflict between the interests of the intellectually disabled adults and those of the child, as outlined by Rönström. Instead, he emphasized just the kind of support measures that Rönström had assessed as insufficient for guaranteeing

the child's development. In addition to this, he also suggested efforts to induce individuals with intellectual disabilities to abstain from having children. Rönström did not comment on this kind of effort, and it remains uncertain whether her opinion was that more children should be taken into custody earlier or that more efficient measures should be taken to prevent individuals with intellectual disabilities from having children. It is, however, interesting to note that while the National Board of Health and Welfare motivated birth control for the intellectually disabled based on concern for the living conditions of the intellectually disabled individual, the concern expressed by Rönström referred to the best interest of the child.

The media debate in early 1980 was followed by a bill introduced to Parliament raising the issue of protecting children with intellectually disabled parents. The bill demanded from Parliament a declaration stating that "the child welfare legislation may not discriminate between children of the mentally disabled and other children". Furthermore, "tolerating poorer protection from society and inadequate living conditions for these children than for children with non-mentally disabled parents" was described as unacceptable (Göransson & Pettersson 1979:2). It was also argued that the rights of the intellectually disabled to an independent life could not be defended at the cost of the child's opportunity to grow up in an environment more conducive to normal development.

It now seems as if one sometimes hesitates to intervene and to place these children in foster homes, as this may be perceived as discriminating against the mentally disabled. (Göransson & Pettersson 1979:1)

The standing committee on social questions recommended the rejection of the proposal, but declared it to be indisputable that children with intellectually disabled parents had the same right as other children to the type of caring and stimulating living environment that was a pre-requisite for a child's normal development and to protection against harmful treatment (*Socialutskottets protokoll* 1979/80:44). In a petition to the minister of Health and Social Affairs in 1980, the social democratic member of parliament Lena Öhrsvik (1979) described a shift in the debate on intellectually disabled parents. After "the agitation campaign against social workers who heartlessly took children away from their parents", the media now, according to Öhrsvik, accused the authorities of lacking interest and initiative, the consequences being that "defenceless children are left unprotected in bad home environments". Öhrsvik too criticised the special treatment of children with intellectually disabled parents. The difference in treatment that she referred to, however, was not that these children were neglected, but rather that they, to a greater extent than other children, were being watched by the authorities (Öhrsvik 1979).

Later the same year, the committee on care of the mentally retarded received a supplementary directive, which commissioned the committee also to consider the issue of intellectually disabled parents and their children (SOU 1981:26). The commission was to elucidate the situation of these children with the aim of meeting their needs for security and care. In its

report, the committee stated that children with intellectually handicapped parents should not be treated differently as a category, but that all children must receive the kind of societal support that their specific situation requires. At the same time, the committee also claimed to aim at individualizing and normalizing the living conditions of intellectually disabled adults (SOU 1981:26).

In an article published in *Psykisk Utvecklingshämning* in 1984, the image of children with intellectually disabled parents being left to their fate out of fear of violating the integrity of the handicapped adult was questioned. The accusations that habilitation services one-sidedly protected the interests of the intellectually disabled parents were claimed to be unfounded. The author, Margareta Liljeqvist (1984), who represented the state commission on habilitation (*Habiliteringsnämnden*), argued that it was indisputable that the best interest of the child should always come before the interests of adults and that intellectually disabled parents should be treated in the same way as other parents whose ability to care for their child was in question. "We want to emphasize", Liljeqvist continued, "that, in a critical situation, the child welfare centre should always put the child's interest first." (Liljeqvist 1984:29). Margareta Nordeman (1999) expressed something similar in her book on intellectual disability and sexuality originally published in 1993. She agreed that individuals with intellectual disabilities had a legal right to have children – although this right was applicable only in relation to conception through coitus, as the right to artificial insemination is limited to persons not considered intellectually disabled. However, she continued, society has a responsibility to guarantee that all children grow up in an environment that furthers their development. Therefore the needs of the child should always be of higher priority than the needs of adults.

In media coverage of the issue of intellectual disability and parenthood in the 1980s, services for the intellectually disabled were accused of showing too much consideration for the parents at the expense of children's rights to societal protection against detrimental treatment in the parental home. At the beginning of the 21st century, the situation was the opposite. On 10 December 2002, a programme in the series *Uppdrag granskning* (Commission: inquiry) with the title "Too stupid to be a parent?" was broadcast on Swedish television. The programme was about a couple with intellectual disabilities living in the small town of Oskarshamn and their young son. According to the facts presented in the programme, the couple was taken to supervised housing directly after leaving the maternity hospital for investigation of their ability to manage their role as parents. After a while, the boy was taken into custody. In the announcement before the programme, taking a child into custody against the will of the parents was compared with coercive sterilization. Further, the standpoint conveyed in the programme was that it was wrong to take the boy, as the couple's failings were perceived as trivial. The programme marked the starting point of a wave of concurring articles with headlines such as "I admit, I have shaken the baby's bottle", "The parents, who were rejected" and "Almost rejected as mum" (Marklund 2002, Kadhammar 2002, Svensson 2002). Moreover, Göran Rosenberg (2003) used

the case to argue for a general strengthening of the biological family in a column with the ironic headline “How much incompetence shall we tolerate in parents?”

The *Uppdrag granskning* programme as well as the articles were critical of the explanations for why the son of the Oskarshamn couple had been taken into custody. The critique was based partly on the programme’s description of the couple’s decisive mistakes as being mistakes any parent could have made. However, the critique against social services also included a general questioning of the right of authorities to interfere in family life. What was being guarded in the reports was the right of parents to integrity. In an article about the child perspective in the Social Services Act, sociologist Gunilla Petersson (2003) described the status of the biological family at the beginning of the 21st century as almost sacred. According to Petersson, the only argument that can warrant encroachment on the family is the best interest of the child. However, neither in the television programme nor in the subsequent newspaper articles was the protection of the integrity of the family put in a discursive state of opposition to the best interest of the child or the child’s right to protection. As a consequence, the assertion of the parents’ right to integrity never had to take place at the expense of ensuring the best interest of the child – which would have been a discursive impossibility.

The television programme was also met with critique. In this critique, the potential conflict between the rights of parents to integrity and the best interest of the child formed the basis for the claim that the former must sometimes be restricted to ensure protection of the latter. In 2003, that is the year after the television programme about the Oskarshamn couple was broadcast, Barbro Hindberg published her book *Barn till föräldrar med utvecklingsstörning* (Children of parents with intellectual disabilities). The initiative to publish the book was taken by Barn-och ungdomsforum (The Forum for Children and Youth), whose aim is to improve the living conditions of children and young people. In the book, Hindberg (2003) accuses the *Uppdrag granskning* programme as well as some of the articles that followed it of disseminating simplified descriptions of reality. According to her, the indignation over taking a child of intellectually disabled parents into custody was caused by the Swedish public’s bad conscience over the sterilization policy of the inter- to post-war years. (Hindberg’s interpretation is in part confirmed by a passage in the National Board of Health and Welfare information booklet from 1990: “Considering ... our tradition of coercive measures regarding these parents (parents with intellectual disabilities; my remark), is it necessary to attach great importance to the legal rights of the parents.” (*SoS-rapport 1990:27*). Hindberg (2003) sees the reluctance to speak about the difficulties parents with intellectual disabilities experience as an expression of the general aim to strengthen and support individuals who are regarded as weak and of the consequent unwillingness to point out their shortcomings. As a result, Hindberg claims, the situation of children with intellectually disabled parents has been ignored.

The discursive positions taken in the various publications discussed above can be categorized as defending either the right of parents and the family to

integrity and immunity against encroachments of state authorities or the right of the child to societal protection against poor home conditions and maltreatment. The first position can be maintained with reference to a general defence of the right of all families to integrity and in addition the right of intellectually disabled parents to be treated no differently from other parents. Furthermore, both positions can be maintained with reference to the best interest of the child – “the biological family must be kept united for the sake of the child” or “the state owes the child protection against maltreatment and unfit parents”. However, in the empirical data discussed above, the best interest of the child was used as an explicit argument only in the latter sense.

### **Discussion**

According to the normalization principle formulated in the late 1960s, the living conditions of persons with intellectual disabilities should correspond as far as possible to those of the population in general. Among other things, this implied the opportunity to encounter people of both sexes and to sexual activity.

The explicit aim of equal living conditions and a normalized adult life, however, did not include childbearing and parenthood. During the whole period from the 1960s to the beginning of the 2000s, parenthood in relation to intellectual disability was discussed as a potential problem. The clear recommendation of the National Board of Health and Welfare was to advise intellectually disabled individuals against becoming parents.

The changed image of the right of persons with intellectual disabilities to integrity and self-determination attained through the normalization principle, however, did influence the ways in which the use of birth control could be recommended to individuals with intellectual disabilities. It became discursively impossible to suggest a coercive application of birth control methods. At the same time, the childbearing of individuals with intellectual disabilities continued to be described as undesirable. Thus, birth control in the late 20th century demanded new discursive strategies. The sterilization policy of the inter- to post-war years was motivated with reference to the best interest of society and of the unborn child. Towards the end of the 20th century, birth control was instead recommended with reference to the individual's own best interest. Birth control and abortion were now described as an opportunity for the intellectually disabled woman. According to the recommendations, the disabled woman was to realize the value of this opportunity with the aid of increased handicap awareness, i.e. the realization of her own limited abilities, and the understanding that a happy adult life does not necessarily include parenthood.

The fact that birth control was now described as an opportunity associated with choice rather than coercion may be understood as an expression of a democratization of discourse, which among other things implies an elimination of overt markers of power. But it may also be interpreted as a strategic adjustment to changes in society that demand new governing techniques. If

the aim is to preserve the *status quo*, the use of discursive democratization as a strategy is, however, associated with risk, as the democratized discourse demands social relations that enable a questioning of power-holders and their objectives (Fairclough 1992). Thus, regarding the discourse on intellectual disability and parenthood one could argue that even if the new means of describing birth control as a matter of choice was aimed at efficiently preventing the intellectually disabled from having children, the fact that birth control was now referred to as an option rather than a compulsion necessitated taking these choices into consideration and thereby making a rejection of the overall objective possible.

During the 1980s and later, the discourse on intellectual disability and parenthood increasingly focused on persons with intellectual disabilities who actually became parents. Individuals with intellectual disabilities were identified as risk parents, and as such they were ascribed a great need for support and supervision. According to the directions of the National Board of Health and Welfare, parents should not be allowed to refuse this support. The main argument for the necessity of measures of support and supervision was concern for the best interest of the child.

When the issue of intellectual disability and parenthood was debated in the media at the beginning of the 1980s, children's right to protection against maltreatment and a harmful environment was said to conflict with the right of parents to integrity as well as the right of persons with intellectual disabilities to equal treatment. Authorities were criticised for not intervening often or soon enough when a child fared badly out of consideration for the intellectually disabled parents – an accusation that representatives for care and habilitation services claimed was unfounded.

The media storm sparked by the *Uppdrag granskning* programme about the couple from Oskarshamn at the beginning of the 2000s instead claimed the opposite. Social services were now accused of breaking up families based on dubious assessments of parents' abilities to care for their children. This description, too, did not remain unchallenged, and it continued to be maintained that the situation of many children with intellectually disabled parents had been ignored out of fear of calling attention to the parents' deficiencies.

One of the key arguments in the 1960s for providing for the needs of intellectually disabled individuals was the categorization of individuals with intellectual disabilities as weak and therefore entitled to special support. The need of the weak for support thus became a question of social justice. At the end of the 20th century, the image of individuals with intellectual disabilities as weak has been questioned, which illustrates a rhetorical shift in Swedish disability policy towards an aim to downplay differences and difficulties and emphasize similarities between people with and without functional disorders (Gustavsson & Szönyi 2004).

According to Johans Tveit Sandvin and Mårten Söder (1996), such questioning of the traditional image of the intellectually disabled individual as weak was paralleled by an increased emphasis on individual initiative in care and services for persons with disabilities. Care and services should be

provided on the individuals' request only, which means the individuals must decide what services they require and then request them, instead of being fitted into a collective one-fits-all care system. The idea is that individuals with intellectual disabilities should not be treated differently, but in the same manner as all other citizens in need of assistance from society. The support that any individual receives thus comes down to their ability to plead their own case before the local authorities. In a system of care and services based on individualized measures and action plans, weakness is increasingly regarded as the creation of a well-meaning and paternalistic welfare state. Therefore, according to Sandvin and Söder (1996), there is no scope for the question of how weak individuals, who perhaps lack the ability or resources to assert their own rights, shall be guaranteed assistance and services in a welfare state based on individualism, freedom of choice and self-determination.

What characterizes the issue of intellectual disability and parenthood at the beginning of the 21st century is ambivalence in relation to the ability of individuals with intellectual disabilities to make independent decisions concerning birth control and parenthood. In the National Board of Health and Welfare publication on parents with intellectual disabilities from 1990, this ambivalence was summarized in the following way:

Parents with intelligence impairments need to be treated as other parents. At the same time, they need their special circumstances to be taken into consideration. (*SoS-rapport 1990:19*)

On the one hand, the right of intellectually disabled individuals to integrity is emphasized, which makes birth control administered with coercion and persuasion or discrimination of intellectually disabled parents impossible to suggest. On the other hand, it is expressed clearly that individuals with intellectual disabilities are viewed as potentially problematic if they become parents, for which reason their childbearing ought to be prevented as far as possible and intellectually disabled parents should receive assistance from social services whether they requested it or not. Thus, on the one hand, persons with intellectual disabilities were ascribed the competence and power of initiative that the individualized services of the modern welfare state required, while, on the other hand, the recommendations regarding intellectual disability and parenthood maintained that persons with intellectual disabilities lacked the ability to make independent decisions regarding this question.

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