Persons with Disabilities as Parents: What is the Problem?
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Background This paper discusses the recent debate on parenting by people with intellectual disabilities in the Netherlands. By and large this debate has been dominated by disastrous examples of child abuse and neglect in families where one or both parents have a disability. Feeding on horror stories the media have construed the issue as one of moral and legal constraint: should people with disabilities be allowed to have children? In view of this construal, many professionals in the field have rejected the debate as irrelevant. In their view the issue is about support, not about constraint.

Aim The national organization for self-advocacy in The Netherlands has claimed the right to parenting based on the principle of equal citizenship. This paper aims at (1) reconstructing and (2) evaluating the positions taken in the Dutch debate since its incipience in 2002, particularly with regard to this principle.

Method A philosophical reconstruction of how the moral principle of equal citizenship structured the Dutch debate on parenting by people with intellectual disabilities, in particular with regard to the nation of ‘good enough parenting’.

Conclusion The analysis shows how the principle of equal citizenship guided research in The Netherlands and how it is crucial in criticizing negative responses that depend on stereotyping of people with intellectual disabilities as parents. It indicates how in at least two instances, these responses can be shown to constitute a case of discrimination against these people.

Introduction

The debate on the issue of parenting by people with intellectual disabilities in the Netherlands in recent years has been construed as an issue of moral and legal constraint. The main question raised has been: should people with disabilities be allowed to have children? The aim of the present paper is to argue that this question is misguided. It erroneously suggests that the decision regarding whether people with intellectual disabilities can become parents is a decision for others to make. Following a recent survey in the Netherlands (Willems et al. 2007) that investigated how families of in which one or both parents have an intellectual disability are performing, the paper questions the assumption that the performance of parents is a function of their individual characteristics. Building upon the results of this survey and upon the international literature it reviews, the aim of the paper is to challenge this assumption and argue for a different approach to parenting by people with intellectual disabilities.

In general, the picture emerging from the survey is that it would be a mistake to regard the performance of parenting primarily as a function of people’s abilities or disabilities. Instead it is much more a function of intertwining factors of social, economic and psychological nature. In this respect, it appears that the picture emerging from the growing research reflects the shift in thinking about intellectual disability in recent decades. As we have learned to see that intellectual disability is the result of intertwining individual and environmental characteristics, much the same appears to be true of the ability and inability to be good enough parents.

Background

The Dutch debate on parenting by people with intellectual disabilities started in 2002 with a report on the use of contraceptives for these people, published by the National Health Council (Health Council of The Netherlands, 2002/14). The report recognized that the principal
reason for contraception is the desire to prevent pregnancy on the part of families who asked for ‘permanent’ measures to make sure their daughters with intellectual disabilities will not become mothers. The reason given was the lack of competency to raise a child ascribed to these daughters. While the international literature was already shifting from a competency based towards a family-based approach, the Dutch debate started primarily in a medical context. This explains why the Health Council played a significant role in how the issue of parenting by people with disabilities was to be discussed.

Given its medical context, the main question raised by the report was whether parents are justified in asking for contraceptives to prevent their daughters from having a baby, eventually against their daughters’ own will. It was argued that the guiding principles in this area could not be derived from the code of medical ethics only.1 The judgement of whether a person with an intellectual disability is competent to raise a child, the report concluded, is not one that doctors are professionally qualified to judge. At this point, the Health Council made a decisive move, namely to suggest the principle of equal citizenship as a normative framework. It stated:

The principle of equal citizenship implies that people with mental retardation must have the opportunity to develop their own sexuality in an appropriate fashion, that they are able (whenever possible) to reach their own decisions on contraception, and that parenthood must not automatically be ruled out or made illusory for people with mental retardation. For a physician, this principle also means being fully bound by the code of medical ethics (http://www.gr.nl/samenvatting.php?ID=547, consulted 11 September 2007).

The direction set out by the Health Council in determining the normative framework for the discussion was followed in a national survey on the same issue held in 2004. This survey of 2004 was commissioned by the Ministry of Health, Welfare and Sports. The Health Council had signalled that there were insufficient data available on how parents with ID in the Netherlands were actually performing. In this respect the international literature provided much more information than was available about the Dutch situation at the time (Willems et al. 2007). The survey was intended to fill this gap. Its goal was to provide empirical data and to establish indicators for why the task of parenting in these families tended to go well. These were the leading questions.

To fill in the details of this background two steps must be taken. First, an overview of the main results of the survey is detailed. Second, the author provides an account of the responses to these results.

The survey

From a sample of about 1500 families in the Netherlands, of which one or both parents have an intellectual disability, the survey found that 33% functioned in a way that qualified as ‘good enough’ parenting. ‘Good enough’ parenting was specified by three conditions: there was no sign that children were abused or neglected, there was no interference from a child protection agency, and there was no court ordered displacement of children in foster care.2 Of the remaining cases 50% failed to meet the three conditions and showed insufficient parenting, while the remaining 16% were in a state of transition; they were considered to be either moving towards ‘good enough’ or towards ‘insufficient’ parenting (Willems et al. 2007).

In summary, the most important findings about factors determining these outcomes found in the qualitative part of the study were: (i) that the condition and the degree of intellectual disability per se was not a strong indicator of success or failure, (ii) that inadequate professional support was a strong indicator of failure, (iii) that the presence of a social network acting in support of the parents was a strong indicator of success and (iv) that people’s unwillingness to accept support and follow advice tended to result in deplorable conditions of family life (Willems et al. 2007).

1I will discuss the criteria specifying ‘good enough parenting’ below to show how they reflect the principle of equal citizenship.

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1This statement must be qualified because there can be medical reasons for wanting to prevent pregnancy. The Executive Summary states that: ‘the most important reason for using contraception is the wish to avoid a pregnancy. This may be motivated by various reasons. Apart from simply not wanting to have a child, there are reasons that will be more common among people with mental retardation than in other circles. These include particular medical (genetic or teratogenic) risks for any child that might be conceived. In addition, the patient’s diminished parental competence may pose a threat to the quality of life or to the welfare of any child that might be conceived. It is this latter reason that the Committee examines most closely’.

The responses

With regard to the responses that these findings met in the debate following upon their publication in the Spring of 2005, three parties to this debate must be distinguished: media, government and professionals. The main response by the media – national newspapers, TV news shows – was to present the findings in a decisively negative way. Notwithstanding the fact of a 33% success rate in terms of ‘good enough’ parenting, the media reported, inaccurately, that in 66% the outcomes were disastrous. This presentation of the findings was frequently accompanied by horror stories showing disastrous examples of child abuse and neglect, suggesting that these stories were representative for the 66% of people whose parenting was insufficient. In general, the tendency of these news reports was to suggest that there was a very serious question arising from this survey, namely whether society should allow people with intellectual disabilities to become parents. In this regard, the debate in the Netherlands is no exception to what has been reported in other contexts: parenting by people with intellectual disabilities is more often perceived as a problem rather than a positive live event (Stenfert Kroese et al. 2002).

Unfortunately, the Dutch government did not distance itself from the way the media reported the results of the survey. This was surprising given the fact that when the secretary of health had commissioned the survey, she had explicitly asked whether there were positive examples of parenting by people with intellectual disability. In responding to its results, however, there was no recognition from the government of the fact that in 33% of all families the answer was indeed positive. Instead, the secretary announced a general policy of ‘discouragement’. Focusing exclusively on the 66% as reported in the media, she took the position that our main concern ought to be with the future of the children that are born within these families. Her argument was that although in principle society needs to support parents with disabilities and their families, the negative results in actual practice showed it is imperative to prevent them from starting a family. Therefore a general policy of discouragement was stated to have priority.3

Unsurprisingly, these responses were disappointing for the professionals and the families who had taken part in the survey. Their expectation in doing so had been to instigate a broad discussion on how to improve support for the families, given the many problems that they face. Many of those actually involved in this area felt that the question of whether society should allow people with disabilities to have children was largely beside the point. They took the view that is confirmed in the international literature: people with disabilities who start families face a number of inter-related problems such as low income, the risk of more than average health problems, often ineffective professional support and social networks, and negative public responses (Booth & Booth 1994; Pixa-Kettner 1998; Tymchuk 1999; Feldman et al. 2002; Llewellyn & McConnell 2002; McConnell & Llewellyn 2005). In a recent study a further complicating factor was identified: a history of child abuse and neglect in these parents themselves as a risk factor for their own children (McGaw et al. 2007). In spite of these complicating and intertwining factors, however, people with intellectual disabilities start families and will continue to do so, regardless of whether others consider that a problem (Tymchuk 1990, 1992). As much of the recent literature shows, there is much that can be improved in terms of support systems and programmes that enable families to maintain parental custody (Honey et al. 1999; Llewellyn & McConnell 2002; Stenfert Kroese et al. 2002; Young and Hawkins 2006; Tarleton & Ward 2007).

Discussion

‘Good enough’ parenting

Before turning to the negative assumptions inherent in the responses, it is important to identify an important point of agreement that emerged from the debate. It regards the standard for measuring the quality of parenting. In line with the report of the Dutch Health Council the survey had proposed equal citizenship as its normative principle, but it took a different direction in setting a standard for judging the performance of parenting. While the Health Council took a quality of life approach, the survey followed the international literature inaugurated by Winnicott and adopted a standard of ‘good enough parenting’ (Winnicott 1974; Llewellyn 1991; Booth & Booth 1994; Swain & Cameron 2003). Obviously any standard guiding judgements on how people are doing as parents will be highly susceptible to moral controversy, given the many different values that

3How such a policy should become operational was never clearly specified. The underlying idea seemed to be that other people – professionals in health care and social work – would be involved in the eventual decisions of people with disabilities of having a child, and that their responsibility was to persuade them to abstain from doing so.
people in a pluralist society may bring to the question of what good parenting is. While it might be expected, therefore, that any such standard will face serious criticism, this did not happen, as a matter of fact, with regard to the standard of ‘good enough’ parenting. To explain why, it is important to see how the researchers accounted for their approach of this standard.

To define ‘good enough’, the study used parameters that are derived from legal categories. Under the laws that guarantee equal citizenship, parents are free to do as pleases them as long as there are no reports that they abuse and/or neglect their children, have no dealings with child protection agencies, and have no child placed under legal custody. ‘Good enough’ parenting is parenting that meets these criteria (Willems et al. 2007, 539).

Whereas any conception of ‘good parenting’ is inevitably loaded with particular ethical values, the standard of ‘good enough parenting’ restricts these values to those that are generally accepted – and enforced – in the public domain of liberal society. Liberal society allows people to run their own families informed by their own values as long as some minimal requirements of parenting are satisfied. These requirements are enshrined in the law. Even though other people may consider your parenting to be seriously defective, this is not accepted as a sufficient ground for the state to interfere, as long as you do not treat your children in a way that violates the law against child abuse. Within the Dutch context, the requirements are, as indicated: no apparent sign of abuse or neglect, no interference from child protection agency, no court ordered displacement of children in foster care. When they meet these conditions, citizens have the right to maintain full jurisdiction over their own families.

Restricting its conception of good enough parenting to legal categories, the survey succeeded in its attempt to neutralize the effect of different value profiles. In this way it secured that parents with intellectual disabilities are not subjected to standards that other citizens would not accept when applied to themselves. Following this account ‘good enough’ parents are citizens whose parenting gives no legitimate reason to limit their constitutional rights as parents.

As it turned out, not a single one among the many comments on the survey rejected its approach to providing a standard for parenting. Presumably, this consensus reflects the conviction that citizens in liberal society all have a stake in accepting this standard. It safeguards their own freedom to pursue their own values in raising a family. Given the continuing tendencies to marginalize people with intellectual disabilities, this is an important fact. It indicates how to secure the principle of equal citizenship for these people in the area of reproduction.

Three comments

Generally speaking the overall mood of the public as reflected in the media seemed to say that for persons with intellectual disabilities having children is not a good idea. Looking a bit closer at the arguments, however, it can be shown that they are based on assumptions that are prejudiced against people with disabilities. In what follows I will look (i) at the anticipated negative outcomes for society as a whole, (ii) at the expected outcomes for parents with disabilities and (iii) the same with regard to their children.

(i) Is the fact that persons with disability start a family bad for society as a whole? Before we answer that question, we are well advised to study the history of enforced sterilization as it occurred in many Western states in the early 20th century on the basis of eugenic legislation (Dorożynski 1997; Tannsjo 1998; Zanskas & Coduti 2007). In the US this practice was enforced by law between 1904 and 1970 in 32 states. It received Supreme Court approval with the famous dictum by Justice Oliver Wendell Holmes writing for the majority in Buck vs. Bell (1927) that ‘three generations of imbeciles are enough’. The main reason for these policies was the protection of society against moral degeneration and unacceptable social costs (Pfeiffer 1994; Bachrach 2004).

Looking back at this history, the politics of enforced sterilization is now generally regarded as a gross denial of the socio-economic determinants of the lives of persons with disabilities in those days. The fate of these people in the rise of industrialized nations was in fact the fate of an underprivileged labour force (Trent 1994). In recent times the truth about the history of enforced sterilization has been acknowledged, which has strengthened the case for acknowledging and protecting their civil rights, at least in some Western countries.

With regard to the present issue, people with disabilities’ wanting to have a family of their own, society would be well advised to remember this history and avoid the same mistake, particularly in Europe. At any rate the practice of enforced sterilization as it existed in most of the 20th century would now likely be outlawed by the European Convention of Human Rights (Kevles 1999; Stansfield et al. 2006).
Key to a different approach is to acknowledge that the problems in families of which one or both parents has an intellectual disability more often than not are a function of socio-economic circumstances rather than of individual characteristics, as is indicated by the qualitative result of the Dutch survey (Willems et al. 2007). Given this result, which corroborates the international literature referred to above, the wiser course of action is to adopt a family approach that looks at the pattern of intertwining individual, social and economic factors, rather than maintain a focus on individual competencies. The first answer to the question of whether people with intellectual disabilities having families is bad for society, then, is that our society should not repeat the mistakes in the early 20th century and its pre-occupation with eugenics.

However, the question raised may be informed by a utilitarian rather than a eugenics perspective and assume that supporting these families is too heavy a burden for the public sector. In that case, the answer is that there appears to be a discrimination issue. To see why, one needs to make a comparison with other policies that support people in their desire to start a family of their own. In this respect, a comparison with the practice of in vitro fertilization will be helpful. A 33% success rate of ‘good enough parenting’ – as found in the Dutch survey – is higher than the success rate of in vitro fertilization that does not rise above 30% in most European countries including the Netherlands (Nyboe Andersen et al. 2004; Kremer et al. 2008). As in both cases, people are supported in creating a family of their own, it is not at all clear why support for people with intellectual disabilities and their families is different in relevant respects from support for infertile couples who want to do the same. To make the case for treating them differently, one would have to argue that in the latter case the quality of family life is usually higher. But this is the kind of argument that the legal definition of ‘good enough parenting’ in liberal society forecloses. Support for families through public means should be equal between citizens whose performance as a family meets the standard of minimal legal requirements. The fact that different families answer to different value profiles is irrelevant from a legal point of view, so that to suggest this difference as a reason for differential treatment of families with disabled parents constitutes a case of discrimination.

In the Netherlands the costs for the provision of assisted reproductive technology like IVF have been shared between private health insurance and public funding.

(ii) The negative responses to the results of the Dutch survey also held the view that the task of parenting was far too demanding for persons with intellectual disabilities, given their limited competencies. This criticism was in effect saying that regarding their desire to start a family people with ID need to be protected in their own interest against themselves. In this respect, it is appropriate to take into account what people themselves tell about their own experiences to show how adequate supports can empower them to achieve their own goals (Tarleton & Ward, 2007). Furthermore, we need to keep in mind what has been argued about adopting a family based rather than a competency-based approach. But apart from these considerations, the criticism in question raises another issue, namely the issue of consistency in disability policy, particularly when it comes from policy makers who otherwise hold strong views about empowerment. In the Netherlands, governmental bodies and their officials together with service agencies have committed themselves to the view that people with intellectual disabilities are entitled to have a life of their own, according to their own values, just like other citizens. In view of this declared support for independent living and self-determination, it is fair to say that people with disabilities have been encouraged for at least a decade to speak up for themselves and to make their own choices in life. Apparently they have been taking this message to heart and are now cashing in from what they have been told. They want to decide about their own lives, which for some means they want to start a family. They decide to have children without asking anybody’s permission to do so.

It is evidently the case, therefore, that in advocating discouragement from starting a family, one is in fact contradicting the success of the politics of integration and normalization (Murphy & Feldman 2002). In view of this success there is something profoundly naïve in the idea of a general policy of discouragement. The plain truth of the matter is that children will be born to people with intellectual disabilities simply because many more of them will live on their own than used to be the case. Being no longer under control of institutions and professionals, they do what other people do: find friends, fall in love and make babies. Unless our society wants to go back to the politics of enforced sterilization, it is very likely that there will be more babies rather than less.

The answer to the objection that people with intellectual disabilities are incompetent to raise a family is, then, that an open-minded inquiry into the facts of the case shows that the Dutch survey does not sustain the view that the condition of intellectual disability per se is
the determining factor of insufficient parenting. Nor is it the case that this condition accounts for their reluctance to cooperate with child protection agencies. Very often people feel threatened by professionals ‘who want to take away their baby’. It may be very well true, therefore, that improving the quality of support services may help people to learn to trust that they can gain from adequate professional support in learning the skills of parenting (Llewellyn & McConnell 2005; McGaw & Newman 2005).

(iii) Finally, the negative responses often emphasize the legitimate interests of the children born to parents with intellectual disabilities. While there is every reason to accept the importance of this consideration, there is nonetheless a problem with this response that regards, once again, an issue of discrimination.

Suppose we would accept that the interests of children born to ‘risk families’ is a sufficient reason for limiting people’s right to parenthood. If we were to count families of which one or both parents has a disability as ‘risk families,’ this would mean to ignore the fact that 33% of these people’s families do reasonably well. The results of the Dutch survey indicate, it may be recalled, that being intellectually disabled is not a strong indicator for insufficient parenting. The facts do not corroborate that they can be disqualified categorically for the task of parenting (McConnell & Llewellyn 2000). If therefore these people are nonetheless singled out as a group to be targeted by a policy of discouragement, then this constitutes a clear case of discrimination.

Discrimination means that people are treated differently for reasons that have no clear relevance to the case at hand. In the present case, the correlation between the condition of intellectual disability and insufficient parenting is scientifically not warranted. If the interests of children are taken to be sufficient reason for such a policy, it should be enforced upon all citizens who fail to secure for their children the standard of minimal legal requirements. There is – both de facto and de jure – no initial reason to single out intellectual disability for this kind of policy. As the Dutch government never announced consideration of this policy to be mandatory for the population as a whole, it must face the charge of acting discriminatorily towards parents with intellectual disability when they are singled out as a group to be targeted by a policy of discouragement.

Conclusions

The previous arguments have only served one purpose, which is to clear the ground for an open minded inquiry to find out what needs to be done in support of families where one or both parents live with the condition of intellectual disability. The explanation of intertwining factors suggested by the Dutch survey needs further exploration. At any rate it indicates that moncausal explanations for insufficient parenting are most likely to be false. It also indicates that designating psychological characteristics of individuals as the differential cause is most likely to be inadequate. There is an inter-relatedness of various causal factors that may be, and often are, involved. Parents with intellectual disability are usually poor, therefore their health status may be lower than that of the average population (Emerson & Hatton 2007). They are usually socially isolated – like other poor people – and as a consequence they lack sufficient means to escape psychological stress. Under these conditions the fact that nonetheless 33% of the people with ID meet the standard of good enough parenting is actually quite surprising. The question to answer is what kind of support programs deal adequately with this complexity, and how professionals in the field of family support can develop the skills to be supportive and empowering, rather than judgemental and discouraging.

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References

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