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PARENTING IN THE LIVES OF PERSONS WITH INTELLECTUAL DISABILITIES

Abstract

The questions of childbearing and parenting in the life of persons with intellectual disabilities are very marginal both in research and professional practice. Although international guidelines emphasize the total social participation and self-determination of persons with disabilities, protectiveness is more common at a local level in connection with sexuality and childbearing. Parenting capacity involves the complex interplay between children and their parents, home and community environments, and family and community services. Hence, our intention is to concentrate on these relationships and to conduct interactive pair interviews with people with intellectual disabilities and relevant people in their lives. In our research we are curious about the opportunities and obstacles in the lives of persons with intellectual disabilities to becoming parents in a variety of living conditions, as well as the characteristics of the parenting roles of women and men with intellectual disabilities.

Keywords: persons with intellectual disabilities, parenting, parent roles.

1. INTRODUCTION AND THEORETICAL BACKGROUND

In our research we examine the possibilities of persons with intellectual disabilities becoming parents. In society we can find many stereotypes and prejudices and all too often we encounter taboo and silence. The questions of childbearing and parenting in the lives of persons with intellectual disabilities are very marginal both in research and professional practice. Becoming a parent is not a necessary condition in the transition to adulthood, but these days the experience of parenting is frequently a determinant element in establishing adult identity. The emphasis is on choice and self-determination. Although international legal framework emphasise the total social participation and self-determination of persons with disabilities (UN CRPD 2006), the topics of sexuality and parenting are extremely sensitive, especially for persons with intellectual disabilities, and protectiveness is more common at a local level (Foley 2002; Taylor Gomez 2012).

The question is how to predict who will be a 'good parent' or an 'adequate parent'.

Willems et al. examined the 'good enough parent' connotation regarding people with disabilities. According to their definition, the basic criterion of a 'good enough parent' includes that there is no abuse, that they do not neglect the child and that there is no legal case of child protection pending in the family. According to the carers interviewed in the survey, 51% of their clients would not be a 'good enough parent'. In the research it was considered a protective factor, i.e. a factor enhancing their ability to become a 'good enough parent', if the person with intellectual disability wanted or was able to follow the advice given by professionals, if there was a good social network around them and if they were accepted as parents by their environment. They

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considered it a success factor if the partner was not disabled, his or her IQ level was higher, capable of asking for help and if there was a strong professional background and support available for them. The greatest difficulty was the lack of acceptance and the bad socio-economic status. But they also emphasised that the interaction of positive and negative factors should be considered (Willems et al. 2007).

Many studies indicate that there is no systemic correlation between intellectual capacity and successful parenting (Aunos et al. 2008).

More and more frequently in the professional literature parenting is interpreted as a social activity in which it is not only the intellectual capacity of the mother or father that determines the quality of parenting. Parenting capacity involves the complex interplay between children and their parents, home and community environments, and family and community services (IASSID SIRG 2008). Hence, our intention is to concentrate on these relationships as well as on relevant people such as carers.

A number of studies examine attitudes towards sexuality and childbearing in the lives of persons with intellectual disabilities.

One of the areas examined was how much housing conditions determined the attitude.

Results differ, and while community-based living is found to be more liberal, ambiguity is typical in all types of residential facilities (Grieve et al. 2009).

Other studies indicate that there is correlation between the attitudes of care professionals and the gender of the person with disabilities. Professionals speak of the sexuality of persons with intellectual disabilities with a variety of gender stereotypes (Young et al. 2012).

Parental roles are closely linked to the female and male roles, so different expectations arise with regard to motherhood and fatherhood and the presence of disability just adds another strand to it.

In recent years, it has been difficult to reconcile the ideal of a 'super mum' lifted to mythical heights with the dominant social role of a women with disabilities which is characterised by eternal dependence and asexuality. Women with disabilities have to prove their competence to bring up children continuously, although in the case of non-disabled mothers this issue is never raised (Kálmán 2014).

The romanticized image of motherhood is hardly compatible with either the mother's or the child's disability. In a biomedical milieu the security of 'healthiness' is expected. In some cases, the mother is identified as responsible when a child is born with disabilities. For example, when the mother's alcohol or drug consumption continues during pregnancy. On the other hand, if the child is born with a disability, the mother has an outstanding responsibility to bring up a 'whole' person (Landsman 2009). If the mother is disabled, giving birth to a child is considered an irresponsible step by which a child with disabilities is born. Bringing up a child with disabilities requires a strong and responsible mother, and this competence is frequently questioned with regard to mothers with disabilities.

Educating children with disabilities requires intensive parental resilience, mainly for mothers. The services and support are often incomplete, so parents should always be available and always be able to solve problems. The autonomy of the child is often influenced by whether the parent is able to give practical support. They have to make efforts in different areas like administrative issues, information-gathering, networking, advocacy and endurance. Parents have to become quasi experts so that their child with disabilities can get on in his everyday life (Saaltink-Oulette-Kuntz 2014).

All this, if the mother is disabled herself, means a lot of difficulty and effort.

Fathers with disability are rarely focused on in research. The fathers' breadwinning role can hardly be reconciled with such inherent features of disability such as

dependence, inactivity, asexuality or childishness. They are frequently unemployed or inactive, but other handicaps too provide a challenge to fathers with disabilities in the labour market. Although the model of a breadwinning father has lost a little of its dominance with the expansion of feminism and the socio-demographic situation, research about fathers with disabilities showed that the traditional, breadwinning image of a father often causes role-conflict especially in fathers staying at home with their children. Researchers drew the attention to the specific experiences of fathers with disability and also to the need for further investigation (Kilkey–Clarke 2010).

Based on these studies we are curious about the opportunities and obstacles in the lives of persons with intellectual disabilities regarding parenthood in a variety of living conditions, as well as the characteristics of the parenting roles of women and men with intellectual disabilities.

2. RESEARCH METHODS

We were working with qualitative methods, mainly with semi-structured interviews. In this study we analysed the parenting possibilities of 20 persons with intellectual disabilities (9 women, 11 men). Our interviewees were between the age of 21 and 47, their average age was 35,5. In this project we will additionally have 32 interactive pair interviews.

We conducted interactive pair interviews with persons with intellectual disabilities and relevant people in their lives.

We selected the pair interview method so that we could follow the interactions between the affected person and the helper, how they related to each other with respect to the subject and what experiences they had while interacting. The key person (parent, helper) can help, among others, to bridge the gaps in communication or to dismantle mistrust towards the interviewer and sometimes can act as a sort of 'interpreter'. If we had held separate interviews, we could have acquired other types of information too, but parenting is a joint activity in which direct relations are decisive, so in our research work we concentrated on how their interaction reflected the attitudes related to the subject.

Based on the framework of disability studies second to the principle of 'Nothing about us without us', we worked with a parent couple with intellectual disabilities (Mercer 2002). They are insider experts, and they participated in the research process (testing the interview questions and analysing the results). Now we would like to present our actual results second to our main research questions.

3. RESULTS

3.1. What are the similarities and differences between parenting in a variety of living conditions?

We examined four types of living conditions: long-term residential institutions, group homes, supported living and family homes.

We found that the personal attitude of carers is more determinant than the type of accommodation. While large institutions are more regulated, regulation is typical in all types of living conditions, even the more liberal supported living. For example, contraception is compulsory in supported living but the choice is more personalised.

We encountered structural barriers to childbearing in all types of accommodation beside many uncertain, unclarified circumstances (e.g. guardianship). In Hungary the legal capacity of persons with intellectual disabilities or mental health problems may be restricted by the guardianship system.

'In the one hand, they are under guardianship. Guardianship does not directly limit childbearing opportunities, but it is highly likely that the authorities may take the child from them despite any possibility that they are capable of caring for a baby. On the other hand, supported living is officially a caring facility for adult persons and not for children' (care professional employed in supported living).

We detected additionally that protection and safety take priority over the self-determination mentioned in the observations of international studies (Bernert 2011).

3.2. What are the similarities and differences in parenting between women and men with intellectual disabilities?

In this part of our analysis we found that in many cases the 'disability role' exaggerates gender roles and concerns about childbearing. Yet greater emphasis is placed on protecting women, because in the most cases they have to take responsibility for contraception.

With regard to the role of parents, we detected uncertainty and unreal perspectives in more protected environments.

We also found women and men with intellectual disabilities living out their parenting ambitions in the role of 'substitute parents', for example as aunts or uncles.

– 'I have accepted that I will not be a father, but I am glad to have a nephew' (31-year-old man).

Dolls also play an important role for women with intellectual disabilities.

– 'I can't have a real baby, I'm sterile. I have dolls but I find it difficult to support them too' (34-year-old woman).

Women interviewees often plan to deal with children in a professional capacity. One of the professionals described the following dilemma:

– 'She would really like to deal with children. But even if she had a nursing qualification, she probably would not get a job, so we are reluctant to allow her to try to study' (care professional, supported living).

Regarding parenting roles in the narratives we realised that several interviewees did not have a good example of parenting to follow, and that in their opinion good parents were ones who 'do not throw away or hurt' their child, or 'do not place them in institutions'.

Many interviewees interpreted parenting roles from a practical viewpoint, focusing on activities centred on the baby and financial considerations. The interviewees made little mention of parental responsibility and education.

3.3. What are the characteristics of gender roles in the narratives of persons with intellectual disabilities?

We asked the interviewees about the characteristics of women and men, and when they consider themselves, feminine or masculine.

So far we have found that women often identify outward appearance (e.g. pretty, trendy) while men tend to emphasise character traits such as seriousness and determination with regard to their respective gender roles. Motherhood and childbearing did not feature as a dominant part of a woman's role in the interviews.

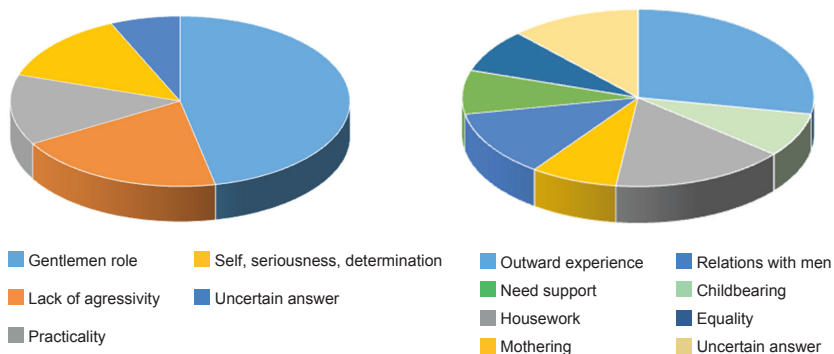


FIGURE 1. WOMAN'S AND MEN'S ROLE IN THE NARRATIVES OF INTERVIEWEES WITH INTELLECTUAL DISABILITIES

3.4. What factors do the interviewees consider a problem when becoming parents?

3.4.1. Social hindering factors / hurdles

Each interviewee expressed what a financial burden it is for the parents to have children. Their income is significantly lower than the majority of employees and for 6 hours work per day they get, on average, 50 thousand HUF a month. Those under guardianship face several factors which hinder their becoming a parent, such as the fact that the guardian determines the amount of money they can use from their wages for what type of expenses. (We found a couple who had to cover the costs of their morning, evening and week-end meals from 8 thousand HUF, this is £ 20 a week.)

Another obstacle is the fact that either a key person (e.g., grandparent) who could help them to bring up children is missing or is too old. In the society of the 'abled' the skills necessary to perform the role of a parent and the tasks related to the care of the children are taken for granted. It is an essential condition to be able to perform successfully things like managing household money, shopping, etc... In our experience, people with intellectual disability take a lot more time and energy to master and use these skills, compared to the majority society and without helper(s) it is almost impossible.

If it is impossible to rely on a helper (because of his or her advanced age) in bringing up children, then this frequently eliminates the desire to have children.

'...I would like to have children, but let me tell you that it makes no sense, partly because I am old, on the other hand Mom could not bring them up... you should not want a child if you cannot bring him up' (43 y. o. woman).

The lack of a proper parental role model (e.g., because of having grown up in an institution), hinders adequate preparation for the role of becoming a parent. Several interviewees explained their inability to become parents with the fact that they did not have a proper role model, since they had grown up in an orphanage.

'...I got into an orphanage at the age of eight. It happened because my parents were unable to provide anything [...] they were like that' (43 y. o. man).

The difficulty of finding a partner and establishing a relationship on their own is an obstacle to becoming a parent.

We came across several examples when people with mild intellectual (mental) disability found it hard to find a partner if the potential partners in their environment had weaker intellectual capabilities than they had. They also needed help in finding proper dating possibilities (internet).

'...they are not at the same level as I am. From this point, it would be quite one-sided... it could not become so deep' (36 y. o. man).

Societal attitudes also provide significant hurdles, especially if any of the above appear in the legislation or in the welfare provision system.

3.4.2. Obstacles deriving from the individual's intellectual disability

It is an individual obstacle if the person has disease awareness, i.e., our interviewees mostly regard their disability an illness, which is an excluding factor when becoming a parent.

'...I dreamt about having a family [...] but I have given up this dream exactly because of my illness... I have to accept that I cannot have a family on my own' (31 y. o. man).

We found several cases where, despite the strong desire for a family on their own, they worried substantially that their condition, which they mostly regard as an illness, could be inherited, so the fear of repetition is also a significant obstacle to having children, which becomes even stronger if their partner is also has intellectual disabilities.

'I don't know. I gave it a thought that God knows if it is good or not good if an ill child is born and then... his mother won't accept him. Because if a child is ill, he won't be so much accepted, and then, if a child is born, it can happen that it will be disabled because the father is ill too' (43 y. o. woman).

Besides, we came across irrational suppositions and fears concerning the process of birth and its consequences.

'Because I am terrified of giving birth... it could happen that my kidney falls off due to the big effort' (24 y. o. woman).

It is noteworthy that some of the persons studied expressed intense concern that, if the mother's age was over 40 years, the child would come into the world with an impairment. Another age (in this case, e.g. 37 years) was also considered a hindrance to having children which, in the case of 'non-disabled' people, would not be a precluding factor in child-bearing.

'...in theory it is risky to make a baby if you are above 40. Anything can happen. Disability or something like that' (24 y. o. man).

At an individual level we also noticed the lack of self-esteem and a very strong sense of incompetence with regard to performing parental tasks. The majority of the interviewees thought that they were unable to bring up a child.

Family members and mostly mothers and adult brothers have an important role in provoking this psychologically painful sensation. The latter in many cases at least make it possible for their family member with disabilities to acquire the joy and the sense of achievement of education by allowing them to act as aunt/uncles, something that otherwise they would not be able to experience as parents.

The background to this sense of incompetence is that they do not feel capable of doing many 'jobs', such as paying for the clothing, schooling, feeding of a child or financing their higher education, nor assuming the other responsibilities of bringing up a child, something that might derive from their previous socialisation.

Many expressed that for 5-7 years bringing up a child shortens significantly the time which the couple could spend on themselves or in common activities they both enjoy.

Another factor acting against having children is that many interviewees were afraid that they would not be able to dedicate the necessary attention or care to their children. Another argument they brought up was that they were unable to handle the problems that might arise and also the lack of knowledge, like e.g., what to do 'if the child starts to cry in the middle of the night'.

Dealing with older children seems easier for them, because in the case of older children they do not feel incompetent and skills like changing nappies are not needed, so this does not create anxieties in them.

Interviewees stated that for both partners a steady and satisfactory relationship is of greater value than the experience of becoming parents.

'...it's better this way as we are' (43 y. o. man).

In our experience, for our interviewees engagement or wedding almost exclusively mean the appearances (e.g., buying an engagement or wedding ring, wearing a glittering wedding dress), and the motivation or the desire for having children derives mostly from the child's physical beauty.

'Q: Would you two like to have a baby?

A: Yes, we would like to. Because always when we look at one, we see, oh, how cute they are and we would like one like that' (24 y. o. man).

It is worth mentioning that even for those who do want to become a parents and explicitly articulate their desire to have children, there is still some ambiguity.

'Well, I don't know, [...] in today's world it is difficult to bring up children' (43 y. o. man).

3.5. *The attitude of the helper to the relationship or to parenthood*

3.5.1. **For people with intellectual disability living in a family environment**

The helper most of the time is the mother, in fewer cases an adult sibling. The relationship between the helper and helped is a very close partnership. Because in most of the cases they are relatives it is very difficult, in everyday life, for the helper to respect the independence of the member with intellectual disabilities of the family and one element of this is not forcing their own ideas on the individual with disabilities about his or her relationship. On the other hand, they also feel responsible for shaping the private life of their loved one, so they act as a protector, e.g., they also split punitively with their child's/sibling's partner, if they see that the partner is harming them.

Although, on the surface, they support that their child with intellectual disabilities to find a partner, and believe that the child indeed needs that, in their narratives they did not think it feasible for their family member to leave the safe family environment. Many times we found that they were happy to accept their child's or sibling's partner in their own home.

'Well, I'm saying to you that if you find somebody who can accept you as you are with this bloody awful nature of yours,... I promise I will accept her as a daughter' (37 y. o. man's mother).

We found examples where one of the parents considers a possible solution to be if they can find an institution where it is permitted for couples to stay together and where they can get practical help with their everyday activities.

'We have thought of them together, even if not independently... what we can see in these institutions is that couples can stay together. I can imagine something like that for him. Where... they have services. It is pretty cool that there are institutions like this' (48 y. o. woman's mother).

Without exception, the members of the family always pay special attention to contraception. It is quite remarkable that in a family the mother supported her son in his plan to undergo voluntary sterilization. It caused her substantial frustration that in the health institution they denied him the medical intervention that would have rendered him infertile.

'Once he came up with the idea completely on his own... that he was ready to go through with it. And the next time when we went to the hospital to get a date for the intervention, the chief nurse noticed in a medical document that er... independent life ... and then she said, 'no way'. And she talked to me as if I had been a useless monster who was ready to persuade her own son to do mean and vicious things... I felt terribly humiliated. I left the hospital thinking now what? The hospital wants my son to increase the population? [...] He is not under guardianship. So they should have accepted his request' (37 y. o. man's mother)

Pursuant to the points (1) and (1a) of Para 187 of the Act on Health (CLIV/1997), sterilisation, for family planning reasons, can only take place if the person concerned is over 40 years of age or has at least three children of his own. Since in the case the interviewee did not meet this criterion at the moment of filing the request, the hospital probably did not refuse to carry out the sterilisation because of disability, but acted lawfully. It became clear from the interview that the mother's frustration was caused by the fact that the hospital failed to inform her and because of the improper style of the communication.

There is a view that persons with intellectual disabilities will not be able to care for their children, therefore the upbringing would become the task of the already aging grandparents and/or adult sibling or, in the worst case, a children's institution.

'How could they have children? I'm not sure that is needed. Not sure. Because... a very good background is needed for that, a helping family. She should not remain alone by any means. Either she gives birth to a child or then... they put him or her into an institution. But if there is a safe place at home, well even then the probability is bigger that the child will also has disabilities. I do not know if I would have the courage once again. I don't know' (48 y. o. woman's mother).

The parents of adults with intellectual disabilities worry that, because of their age or being worn out, they are not suitable any more to bring up a possibly disabled grandchild. They think it is very irresponsible if an intellectually disabled person gives birth to a child just because they feel like playing with a doll, or if parents approve it because they want a grandchild. The examples of parents with intellectual disabilities having children is also a deterrent.

'...I know that now it is very much encouraged that in a given case they could have children. I heard that, but then I gave it a thought that what if the parents, in fact, are in a condition that they are unable to bring up that child, if they are unable to provide schooling, then what? To give birth to a child just because they have the right to, then give birth to a child for an institution, furthermore... I have heard of a case where the child was mentally healthy and, as he started to grow, looked around in the family, then very ugly identity problems arose in him' (37 y. o. man's mother).

Even parents, who verbally support their children finding a partner, ignore or reject in a hidden way the possibility of childbearing. A young 24 year old person, for example, with a steady one-year-long partnership and plans to get married was not permitted to spend the night together with his partner in his parents' house. It became evident from the interview, and from the declaration of the young person's helper, that the parents opposed their child's sexual relationship in order to avoid unwanted pregnancy and not because of any religious conviction.

3.5.2. For those living in small groups in sheltered accommodation

In the sheltered homes we examined we found that the helpers have an attitude of acceptance towards the issue of having a partner, and helpers have a tight and well-functioning relationship with the residents.

This is especially valid in the case of long-lasting, steady relationships, where the clients consult their helpers even about personal issues and who comply with the norms and expectations of the institution.

'Everything is tidy and clean... they are really decent people. They keep their room tidy. They are both clients' (helpers' comments).

Yet both the management of the institution and the helpers have to be informed if a relationship is established as well as when they intend to live together.

'The manager and the helper have to know about everything, but is permitted' (helper of a 47 y. o. woman).

Having a child is possible in principle, yet the majority of helpers think that the high need of the person with disabilities for help does not permit it, since even parents with mild intellectual disabilities require continuous help.

'...they need an incredible amount of help to bring up children. Everything that is related to schooling, hospital care, education or teaching. In their everyday routine, they need help in everything. Everything' (37 y. o. man's helper).

During our research we also found opinions that, because of the deficiencies of public social care system, both the families and the institutions have the right to decide whether they want to assume the upbringing of child with physical or intellectual disabilities.

'...while there is no well-structured and usable system able to provide assistance in bringing up a child with physical or intellectual disabilities to born into a family, then you cannot take away from either the institution or the family the right to decide whether they are ready to bring up the child or not' (37 y. o. man's helper).

3.5.3. Supported living

In the Supported Living-Houses there is a possibility to provide a more independent life in separate houses to the adults with disabilities, still within a small group. In the different forms of supported living we examined couples, whose relationship was longer than one year, were enabled to live together. After having attended a training course, the couple can live in separate apartments or rooms but surrounded by a small group. This type of provision permits a higher degree of independence, whilst still receiving help, which is very favourable to creating and maintaining relationships.

People with intellectual disabilities can lead an independent life only with the assistance of their helpers. There is a partnership between the helpers and the residents of the supported living. In our experience the helpers are open-minded and their attitude is very supportive of relationships being initiated or even when the person with disabilities want to get married or have children, if their clients' mental and psychological maturity permit that.

The helpers' main principle is that they provide help only in issues where the clients need it or explicitly request it. Their view is that the main criterion for becoming independent is not whether they have children or not, but to be able to master the everyday routines and skill necessary to lead an independent life, like managing

money, doing the house chores or assuming responsibility for their actions with regard to other people.

As mentioned before, in this form of housing too there are structural obstacles and the helpers have uncertainty with regard to the existing frameworks. They consider it an important condition for having a child that at least one of the partners should be out of guardianship and have a place where to live at (e.g., a rented flat) and that the couple could receive practical help from home to bring up the child, to find a proper working place and to learn how to cope with the household chores.

Under current legislation, people under partially limited guardianship are free to contract marriage, but the marriage of those under fully limited guardianship is not valid [Civil Code point (1) para 4:10]. If a person under full guardianship would like to get married, then the limited guardianship should either be eliminated or a request should be filed to change the fully limited guardianship into a partially limited one. Guardians usually oppose very strongly the requests for eliminating the guardianship submitted with the assistance of the helpers.

Their main argument is what is going to happen if the person under guardianship becomes alone because of losing his or her partner in future. The reason of the resistance of the carers is not an unreasonable limitation of the rights of the persons with disabilities, but the fact that they want them to maintain a safe life, even if this contradicts or hinders the desire of becoming independent.

4. SUMMARY

In our research we examined the possibilities of adults with disabilities becoming parents. According to our results so far, we found that the possibilities both for having partners and for bearing a child are hindered by many social hurdles. The immediate environment and particularly the relatives of the adults with disabilities have a decisive role in whether or not they can overcome these challenges. By means of further interviews we will try to understand in detail the experiences of adults with disabilities becoming parents.

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