

Toolkit

Talking about children

Handbook

Instructions and
Background information



Preface

In recent years, ASVZ has acquired a great deal of knowledge and experience regarding the topic of a desire to have a child by people with intellectual disabilities. In 2008-2009, we compiled our knowledge and experience in The Toolkit, 'Children, what does that involve?' It is a toolkit with games, instructions and recommendations for how to engage clients, parents and fellow professional care workers in discussions about this topic. With this toolkit, we won the Dutch Disability Care award for the best Product for Actual Practice in 2010, an award set up by the Dutch Association of Health Care Providers for People with Disabilities (VGN).

There is still a great demand for information and experiences regarding this issue. That is why we used the award money to construct this website. You can download all the material from the web version of The Toolkit free of charge. This is how you can benefit from everything that has been developed. The site does, however, offer more possibilities. With the

addition of your knowledge and experience we can continually improve it. The site is available in both English and Dutch. This is an excellent medium to promote international attention for the topic of the desire to have a child by people with intellectual disabilities; it also serves as a medium through which we can share and develop our knowledge and experience internationally.

Sliedrecht, July 2012

On behalf of ASVZ,

Marja Hodes

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1

Context

What is important in your life?
Health, happiness, friends,
love, money, work, a home,
a child, a family...

Ask people you meet by chance what they think is important in their lives. You will often hear things such as: health, happiness, friendship, love, money, work, a home, a family, a child. This is no different for people with an intellectual disability. They too want the same things that make life pleasant and meaningful. They want to participate in society and have a sense of inclusion: equal citizenship. Respect and being taken seriously are essential components for this.

Since the start of the 1990s, the Dutch government has been enforcing a policy that focuses on the active participation in society by people with an intellectual disability. The impact of the paradigm of citizenship as defined by the new models of the ICF (International Classification of Functioning, Disability and Health) and the AAIDD (American Association on Intellectual and Developmental Disabilities – formerly the AAMR) emphasizes that citizens with an intellectual disability should be able to choose for themselves where and with whom they want to live, work and spend their leisure time. By the same token, this means that relationships, including sexual relationships, and having a family are becoming a more routine option.

In October 2002, the Health Council published a report on contraception in people who have an intellectual disability.

In the interest of the client, the Health Council asserted that switching over to compulsory contraceptives may be administered only in cases of incompetence and under strict conditions. They based this on the doctrine of equivalent citizenship. Accordingly, in the summary of this report we read that people with an intellectual disability should have the possibility of exploring their own sexuality in a responsible way; that they should make their own decisions about their own use of contraceptives as much as possible; and that parenthood for people with an intellectual disability may not be preemptively ruled out.

This caused a substantial amount of political commotion. After gathering information in the field, the sitting secretary of state of the

Ministry of Public Health, Welfare and Sport at the time concluded that a deterrent policy was more suitable in the broader interest of society. However, extensive research on the factual state of affairs regarding parenthood by people with an intellectual disability was lacking. The years thereafter were characterized by repetitively heated discussions between advocates and opponents of deterrent, which were mainly fueled by media reports about failing parenthood by parents with an intellectual disability with occasional disastrous consequences for the child involved.

In 2004, the Ministry of Health, Welfare and Sport commissioned a study to collect factual data regarding parenthood by people with an intellectual disability. This resulted in the research report, 'Interplay of factors' (Samenspel van factoren) in 2005.

The study focused on more than 1500 families, of which one or both parents had an intellectual disability. The researchers concluded that parenthood was sufficient in approximately one third of these families. There were distressing situations in one sixth of the families who participated, and parenting was deficient in somewhat more than half of the families.

Further, the factors that contribute to 'good enough parenthood' were studied. The researchers used the balance model to accomplish this. This is a model with which the risk factors (burden on the family) and protective factors (resilience) can be analyzed together. The conclusion was that it was not specific to one or a few factors, but that it involved an interplay of factors. Commensurate with the presence of more risk factors, more protective factors are needed. A very important conclusion was that **an intellectual disability is not a determining factor for neither successful nor unsuccessful parenthood.**

This is in accordance with what already had been concluded in earlier studies abroad. The presence of a supportive social network turns out to be crucial for increasing the chance of successful parenthood by people with an intellectual disability.

On 1 March 2006, former state secretary Ross from the Ministry of Public Health, Welfare and Sport sent a letter to the Dutch House of Representatives informing that they discontinue the deterrent policy for cases where responsible parenthood is only possible as a result of a supportive network. That was also a clear milestone in the societal discussion about this issue. The fact remains that an increasing number of young mothers/parents with an intellectual disability continue to present themselves at healthcare organizations.

After the appearance of the research report, four healthcare organizations (ASVZ, Philadelphia, Gemiva-SVG and Dichterbij) established the 'Werkgezelschap Ouderschap en Kinderwens' (WOK): a task force for people with intellectual disabilities who want and have children. The motive for this was an inability to provide adequate support on the work floor regarding parenthood and the desire to have a child. The task force has since become the designated liaison body in the Netherlands specialized in information regarding the desire to have a child and parenthood for people with an intellectual disability. This task force initiates scientific research, it participates in carrying out research, and it is responsible for the dissemination of the results. All important parties, including national parties, gather around the table together as valuable interlocutors. This task force also takes initiatives to support professionals in actual practical settings by providing training sessions, including the E-learning project called 'A Look at the Desire to Have a Child.' Finally, the task force compiles knowledge and experience, and provides an active contribution to the societal debate regarding the desire to have a child and parenthood by people with an intellectual disability.

ASVZ is an important partner in all of these developments. It is one of the initiators of this task force. ASVZ has made a major contribution to the development of the E-learning project 'A Look at the Desire to Have a Child.' In addition, ASVZ has provided the scientific community with one of the female doctoral researchers for the scientific study 'What works for parents with intellectual disabilities?', begun in

collaboration with the Free University (VU) in 2008.

The study 'What Works for parents with intellectual disabilities?' has three specializations, based on the three success factors from the study 'Interplay of Factors':

- Requesting and accepting support: how can we make sure that parents more frequently ask for support and accept the support offered?
- Good methodical parenting support: the development and testing of an effective video-feedback method to enhance the sensitivity of parents with an intellectual disability.
- Supportive network: how can we make sure the family and friends of the parents want to offer support more often?

The results of this study will be published in 2013.

In different organizations we currently see advocates of and opponents to the option of parenthood by people with an intellectual disability. The discussion about the desire to have a child is directly related to this. There are organizations who use discouragement as its fundamental point of view when it comes to supportive care of clients who want to have a child. Some organizations have explicitly incorporated that into their approach to care. Other organizations choose to provide the best support possible for people with intellectual disability so they can make a responsible choice. Parenthood is hence not preemptively ruled out.

Then there are other organizations that are searching for a perspective that fits with their viewpoint or identity.

How can you do justice to the clients in your own organization who either implicitly or explicitly indicate they would like to have a child? How can you do justice to the clients who get pregnant either by choice or accidentally, and come to you as professional care worker for support? Knowing what your own ideas are about this topic and what your organization's viewpoint is on the topic, is the first step. Before getting into that, we will briefly talk about the 'group of clients' in question. Who are they and where do we come across them in our society?

2

Who does this concern?

The chance is great that you, as professional care worker, will sooner or later have something to do with clients who want to have a child.

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Officially, when we are talking about people with an intellectual disability, we are talking about people with an IQ under 70/75, and problems with social adaptation, the ability to adapt to the requirements that a society places on them in accordance with their age and cultural background.

In actual practice, however, we focus on people with an IQ between 70 and 85 as well. This group often requires more intensive supportive care, and psychiatric problems regularly play a role.

Regarding the topic of the desire to have a child, we are mainly dealing with a group of people with an IQ of approximately 50 to 85. Even though the report 'Interplay of factors' reports that there are no parents with an IQ lower than 50, actual practice has shown that these parents do exist. This group is even showing a slight increase in parenthood. We will have to keep this in mind.

Where do we come across people with an intellectual disability and a desire to have a child?

Of course there is a wide variety of people with an intellectual disability and a desire to have a child. We see them in all sorts of places within our society and in a range of circumstances: They go to school or are following a vocational training program. Others skip school and hang around. They live with their parents or they live alone, with supportive care or otherwise. There are also people who live in a supported living

arrangement or in a residential facility located on the campus of an organization. There are also those who have no home and roam the streets. They work in private companies, at a sheltered workplace, at a daycare center, or an activity center. There are also those who do not work, receiving welfare benefits, others have absolutely no income.

Some have a steady partner. Others do not have a partner, or have multiple partners. They do not yet have a child. Or some of them have a child and want more children. They raise them themselves, some without any help, or other people take full care of their child(ren) for them.

Some can live within their means. Others have much debt.

Sometimes some of them can count on support from their family, neighbors, or friends. There are, however, also people who have to find everything out on their own.

It is good to be aware that you can come across people with an intellectual disability and a desire to have a child anywhere, and sometimes you have to look for them.

The chance is great that you, as professional care worker, will sooner or later have something to do with clients who want to have a child.

3

Start with yourself: what are your perspectives as a professional care worker?

What is your viewpoint on the desire to have a child and parenthood by people with an intellectual disability? Does that affect the way in which you, as professional care worker, react to a client who wants to have a child?

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People with an intellectual disability have a right to be supported for giving their life and future meaning. When a desire to have a child is a part of that, the client has to be able to count on proper supportive care, which also has a viewpoint based on that vision.

In actual practice we still see that the moment a client expresses a desire to have a child, or when there is suspicion of their desire to have a child, all sorts of alarm bells go off immediately. Doubts about parental competence and concerns about the development and well-being of the child often result in professional care workers approaching the topic with a sense of anxiety. There is an almost automatic control mechanism that kicks in, and either consciously or unconsciously we convey: 'Don't do it!'

In any case, these are not the thoughts that would help us provide appropriate support. Preemptively placing a risk label on the issue may result in the potential future parents turning away from us rather than having us actually assist them.

We already know that many parents with an intellectual disability have made the decision to have a child autonomously, without saying anything to the family, professional care workers or doctor. This is not the way they would like it to be, but their experience has shown them that people in their social surroundings often get negative reactions as soon as they mention their desire to have a child.

The person usually does not notice or does not experience that such reactions are motivated by justifiable concern.

Listening to clients and jointly exploring what they see for their future, even if it means having a child, allows for the creation of a basis of support. And this can only be achieved if there is a respectful relationship between the client and professional care workers. Here lies an important task for professional care workers, managers, (educational) psychologists, doctors, and social workers.

What can you do as professional care worker?

What is your viewpoint on the desire to have a child and parenthood by people with an intellectual disability? Does that affect the way in which you, as professional care worker, react to a client who wants to have a child? By the same token, it determines if and how you are able to provide support to the client in making as responsible a choice as possible.

Do some self-reflection regarding your thoughts on the topic of people with an intellectual disability who want to have a child and be a parent. Do this before you are confronted with one of your clients who may want to have a child.

Think about a number of different clients you have. For whom would you be able to do this and for whom not? What are the arguments? Think about what your first response would be if one of your clients said she/he wanted a child. What would you say? What would you do? What are you projecting? Exchange ideas with colleagues.

Perhaps you think: the desire to have a child is not an issue for the clients with whom I work. Think clearly if this assumption is correct. Can you open your mind to the thought that it is possible that you might come across a client who wants to have a child?

Look up what your organization's viewpoint is on this topic. Is there one? Is that stated on paper or on the intranet? Do you endorse the viewpoint? Is the viewpoint reflected in actual practice? How can you make a connection between your viewpoint and that of your organization? If there is no viewpoint, what could you do about that? Have team meetings or organizational meetings dedicated to this topic. For suggestions, see [Desire to have a child: looking at options](#).

The topic of the desire to have children turns out to be as great a taboo as the topic of sexuality. This is not only about the client, but mainly about yourself as professional care worker. You therefore have to have a good idea about what your own values and standards are regarding this topic. This does not apply exclusively to the professional care workers on the direct work floor. Managers, (educational) psychologists and doctors must also be aware of their personal viewpoints and be able to reconcile this stand with the organization's viewpoint.

Managers, (educational) psychologists and doctors must also be aware of their personal viewpoints and be able to reconcile this stand with the organization's viewpoint. One way of doing this is the place the topic of a desire to have a child high on the agenda and to discuss it at various levels of the organization. You can use the game [Viewpoint on viewpoint](#) for this.

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The topic of the desire to have children turns out to be as great a taboo as the topic of sexuality.

4

Thinking about the desire to have a child: always work together!

Talk with the client and make it clear that it is crucial to think seriously about taking such an enormous step in life such as 'having' a child.

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Some professional care workers almost feel honored that a client chooses them to discuss her/his desire to have a child. Others, in contrast, have a loyalty conflict when a client has a desire to have a child, certainly when the client expresses a wish to speak to nobody at all about it further. Then there are those who wonder: “Who am I that I should interfere with such a private issue as this?”

Finding your way about the topic of a desire to have a child is never really an individual matter. Whether you are a professional personal care worker, a (educational) psychologist, a doctor, or a manager, the client's desire to have a child should always be dealt with from several perspectives. This requires a collective responsibility. **Therefore you must always work together.**

Collectively you can mean more to the client. Collectively you can more easily let go of your personal standards and values. Collectively you can also take action in accordance with the vision that was agreed upon within your organization. Therefore, from the beginning work collectively with several disciplines: **work multidisciplinary.**

What can you do?

Make sure that the organization has a guideline that contains information about what to do when a client wants to have a child.

It is often a professional direct care worker who first hears of this or suspects that a client is thinking about children. It is important to discuss this with the managers and (educational) psychologist responsible for the client. Collectively they can then decide with whom they should further consult.

Some organizations choose to consult with an established multidisciplinary team. There have also been good experiences with multidisciplinary teams that have been collectively appointed on an ad hoc basis. A multidisciplinary team always comprises a professional direct care worker (personal care worker, family care worker), a manager, and a (educational) psychologist. When needed, the team can be expanded with a doctor and a social worker.

Many clients also have professional care workers from other organizations. A very broad circle of professional care workers are commonly involved. Make sure that these care workers can also play a role in the process when it is needed.

Above all, 'Always work together' also means: **always work together with the client.** She/he should be treated with respect. So do not go behind the client's back to give an account of everything in detail.

Talk with the client and make it clear that it is crucial to think seriously about taking such an enormous step in life such as 'having' a child. Also tell the client that it is better to weigh up all the pros and cons with several people. Even people without an intellectual disability first think seriously about this and have discussions about these types of huge decisions in their lives with other people they know. Also tell the client that you want to protect her/him from taking on too great a burden. Make an overview with the client about who she/he wants to have involved in this important topic. This could be family and friends, but also professional care workers. The game **Who's there to support you?** shows you how to make an overview.

5

Talking about the future is also talking about whether or not you will have a child

We know that people with intellectual disabilities often have difficulty making choices and difficulty comprehending the consequences of choices over the long term.

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What kind of the things do you want in your life? Which training program do you want to follow? What type of work would you like to do? Where would you like to live? With whom? All of these are questions that are about the future.

Talking about your own future is important. Sharing your ideas and wishes with other people also enables you to explore what the possibilities are. By the same token, you are able to identify the things you need or the things you have to do to realize these wishes. This can create a meaningful and realistic life perspective. This applies to people without an intellectual disability as much as it does to people with an intellectual disability.

Talking about the future involves all domains of life: health, home, work, leisure time, finances, relationships, friendships, and family. The decision about whether or not to have a child can become a straightforward topic of discussion when talking about the future. Many parents and professional care workers are hesitant regarding discussions about this issue. Although, avoiding discussions about this may create an intensely biased focus on the topic.

Starting discussions in a natural way at an early stage and allowing it to be a component of a total life plan removes some of the emotionality of the subject. It also can help explore the reasons why someone wants children as well as all the things that are needed to be a good

mother or father. This is similar to what you do to explore and search for the type of work that suits someone. When doing this you do not just look at the possibilities, but also at the limitations.

We know that people with intellectual disabilities often have difficulty making choices and difficulty comprehending the consequences of choices over the long term. The ability to self-reflect and the capacity for self-insight are also not always fully developed. Further, we know that to some extent, they may need support or supervision in order to be able to bear the responsibilities that accompany the different domains of life and to carry out the tasks that comprise them.

Therefore, along with the client, make separate (long-term or short-term) plans for the future for each of the domains of life. Look to see if she/he is satisfied with each domain. What would she/he like to change? What would have to happen to make those changes and who could support her/him in making those changes?

Talking about the future and making a plan for the future, or a personal life plan, is something we can provide for people with an intellectual disability. The desire to have a child can be one of the topics included in that.

What can you do?

a. Children with an intellectual disability in their family of origin.

What are all the things you have to do or can do when you are a mother or a father?

When children are at a very young age, we also unconsciously give them information about how to raise children. That is just part of learning appropriate social behavior.

For example: when children play house when they are toddlers/pre-schoolers, we often say something when a doll falls to the floor or if the child picks it up too roughly. And when children have reached the age of primary school, you can talk about the kinds of things you have to do as a parent: getting out of bed when a child cries, doing the laundry, cooking, helping with homework, the list is endless.

Discussions about the tasks and responsibilities of parenthood are essential when talking about parenthood. This also applies to children with an intellectual disability. Therefore, convey to parents that within their family, they could also speak about the topic of 'how to parent' with their children who have an intellectual disability. This can take place when the children are at a young age and in a straightforward way as it is done with children who do not have an intellectual disability.

The future is a topic that is gradually discussed more explicitly as a child approaches adolescence. That starts by thinking about

making the right choice in schools to attend and perhaps also what she/he will do after that. You are able to lay out plans for the future with someone at this age if you sit with them and explore what she/he wants to do. For example: I want to save money for buying a scooter or mp3 player. Or perhaps: I want friends to go to the movies with or to go shopping with. Maybe: I want to live on my own some day. Then you explore what is necessary to achieve this. This also applies to other domains of life. Together you jointly investigate what someone's skills are: what am I able to do, and what do I still have to learn? In addition, you also teach the youth to take her/his limitations into consideration: I can do this, or I can only do this with assistance. You also find out who is able to support her/him to realize those goals.

A personal life plan or a plan for the future should also be included in the supportive care provided to a youth who has an intellectual disability. An example of how you could do this would be to play the 'What I wish' card game together. This game can provide you with an impression of the way in which the youth perceives certain aspects of her/his life. What is she/he satisfied with? What could be different? What action are we going to take for that?

Discussions about the tasks and responsibilities of parenthood are essential when talking about parenthood.

The youth can play the card game with you alone, but she/he can also play it with her/his parents as well as with other family members too. By turning it into a family meeting, family members can be involved in thinking about the future in a positive way. The support of the family for the actualization of a wish can then immediately become a topic in the discussion.

Along with taking time to think about the future and how it will look, it is also important to include the topic of the desire to have a child. Attention can also be given to all the additional things that are involved when you have to raise a child. This is not meant to encourage the youth, but rather to guard her/him from unrealistic expectations and a major burden in the future. At this stage, sex education takes an important place in parenting. Talking about the desire to have a child also belongs in sex education. Having children is a big responsibility and you have to learn many things to be able to do it. It is not sensible to have children so soon. Hence, what can you do to prevent that?

Children are confronted with issues about sexuality at an increasingly younger age.

In addition, they are even sexually active at an increasingly younger age. This also applies to children with an intellectual disability. A child should know that you have to use contraception when you want to have sex without getting pregnant. Of course this means that she/he has to learn how you do that. This can prevent a potentially unwanted pregnancy. Sex education can also protect a child from sexual abuse. She/he should know that sex against your will is wrong. They also need to know that people cannot touch you however they want to.

Sex education and a desire to have a child are issues that should be discussed extensively at school as well as at home. Sex education is, however, not a replacement for making the desire to have a child a topic worthy of its own open discussion.

We know from research that sex education mainly addresses the prevention of pregnancy (by means of contraception), but that the discussion of and the consequences of the desire to have a child are discussed seldom or never.

Talking with young people and their parents about the future, including the topic of the desire to have a child, should be a straightforward routine part of health services provisions. Needless to say, other professional care workers, such as social workers and the school, are also responsible for this. It could also be appropriately placed within the basic curriculum of the education subject of 'Health care.'

b. Youths/young adults with an intellectual disability who live independently or in a residential facility

As a professional care worker you often come in contact with a youth or young adult only when she/he have left the family of origin to go live independently or in a residential facility.

As soon as there is a care giving relationship with a client, it is important to get an impression of her/him. Specifically, formation of a good impression is the basis for successful supervision or support. A personal life plan or plan for the future can be part of that initial stage of the care giving relationship. The aims are to get acquainted with the client's wishes together with the client, to examine which actions need to be taken, and to see who would be able to support the client.

You can use the **What I wish** card game to create a plan for the future or a life plan. Inventory what the client wants in all the domains of life. Write down all the wishes and jointly think about what is needed to realize them: which competencies do you have, what can you learn, and what are your limitations that you have to keep in mind?

In your attempt to gain as complete an impression as possible, you can also ask clients if they want to have a child and if it would be in the near future or later. The more we think of this topic as being straightforward, the more candid the client will be. However, you should be sensitive to the amount with which the client can deal with this topic. You must make sure that you do not create any false expectations and that you do not inadvertently encourage her/him to have a child.

c. Caring for parents

Many parents of young adults with an intellectual disability are concerned about their child's future. One of the greatest concerns is possible parenthood. They have their doubts as to whether their daughter or son can deal with parenthood. They also wonder about how their grandchild will be taken care of and raised? Will that child's needs be met?

Research has shown that parents with an intellectual disability who have a good supportive social network, are better parents than those who do not have that network. The child's grandparents have an important role in this. The prospect of having a second period of parenthood with many additional concerns, instead of simply being able to enjoy grandparenthood, is really too much for a number of parents.

It is also necessary to have dialogue with parents about this at an early stage. A special brochure for this topic was created: **My child wants a child.**

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Many parents of young adults with an intellectual disability are concerned about their child's future. One of the greatest concerns is possible parenthood of their daughter or son.

6

**In discussion with people with
an intellectual disability:
I want a child**

Listen! The client has to be able
to tell her or his story.

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Professional care workers and family members become aware of the desire to have a child of someone with an intellectual disability in different ways. It may be that the client talks about it straightforwardly. For example: 'I want a child because my sister also has one.' Or: "we live together now, so now we also want a child.' It may also be expressed more indirectly. You notice that they express much interest in matters concerning babies: they pay a lot of attention to baby clothes, are always looking in baby strollers, or they look fondly at young children around them. You might also suddenly be faced with a *fait accompli* that a client is already pregnant.

The attention our society places on family and the value of it that is held so dear, means that people with an intellectual disability also have the feeling that they should have a child; that you are incomplete without a child. You can only be happy if you have children. A home, a child, and one on the way: that is the ideal image. It is also common that people with an intellectual disability really do not want much more than having the feeling that they are just like everyone else. From this perspective, it is important to investigate the significance the client places on having a child.

What can you do?

The most important thing you can do is let the 'desire to have a child' be there. That is not the same as approving or encouraging that a child arrives. It is however, important that the client tells her or his story without any external interpretations or prejudices. You will notice that taking this position creates the space necessary for discussion about the desire to have a child.

For more concrete guidelines, see [Talking about your desire to have a child](#).

The next step is to explore what the significance is of the client's desire to have a child. Take some time to think about the following questions with the client: Why do you want a child? Is it so that you think you'll be like everyone else? Is it so that you'll have something to cuddle? Above all, find out if the desire to have a child also means a desire to be a parent: does this person really want to be a mother or father, and what does all that involve? For raising awareness about this aspect, use: [Do I know what that involves?](#)

You can have separate individual sessions with each partner. If the desire to have a child comes from a single female client, the discussion should turn to why she is choosing to have a child on her own, and if it is a realistic option.

The significance of having a child in someone's life may also be explored in a group session with several of the people involved (clients, parents, professional care workers). Another option to explore the significance this decision has for the client is to choose to invite to a session one or more people with an intellectual disability who have decided not to have children. They would also be able to tell what type of activities they have chosen to make their lives meaningful. To do this in the Netherlands you can contact *the Landelijke Federatie Belangenverenigingen 'Onderling Sterk'*, this is a Dutch national federation of self advocacy dedicated to serving the needs of and run by persons with an intellectual disability collectively. Members of this organization willingly provide support at meetings or sessions were the issue of the desire to have a child is being addressed. They also have regional branches.

7

**In discussion with people with an intellectual disability:
I want to become a mother/father**

Daring to ask for support and to be able to accept support is an important protective factor.

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Discussions about parenthood for people with an intellectual disability flare up. For a long time, there have been fierce opponents in the Netherlands who refer to the negative consequences. There are also people who refer to fundamental human rights with regard to the choice to either have a child or not. Then there is another group that refers to the right to safety and protection of the child, or unborn child.

What do we know about parenthood by people with an intellectual disability?

As mentioned in the first chapter, a large-scale study on the risk factors and the protective factors was carried out in the Netherlands in 2004/2005. This study resulted in the research report, 'Interplay of factors' (Samenspel van factoren). The title of the report says it all: 'good enough parenthood' is determined by an interplay of factors.

An important finding from this study was that the degree of the intellectual disability was in fact a risk factor, but not the most determining factor for successful parenthood. The willingness to request support and accept advice turned out to be a very important protective factor, along with the presence of a supportive social network and good professional support.

What can you do?

Effectively invest in your relationship with the client. The probability is greater that she/he will talk about the subject of the desire to have a child at an early stage if there is a trusting relationship.

On top of that, without a good trusting relationship, the willingness to ask for support and accept advice will also be less present at a later phase.

The ability to accept support and ask for support is an important protective factor. Discuss this with the client. You also do not have to make the decision to have a child or not on your own. Consult with the client about who she/he would like to involve in this.

A client's social network is crucial for the chance of successful parenthood by people with an intellectual disability. Always make an overview of her/his social network with the client. Do that in three phases: Clearly define with the client who is important to her/him. Then identify the people that the client can discuss her/his desire to have a child. Finally, identify who would be the important people when the child arrives. For that use: **Who's there to support you?**

Because a supportive social network is such a determining factor for achieving 'good enough parenthood', it is important to involve the principal people from this network in this process as early as possible. Find out if there is a family member or several of them who could be there as support. If they are in the network overview, then discuss with the client how these people could best be called upon for support. Organize sessions in which a group discussion can take place regarding what is and is not possible. If it is apparent that the client's social network is very limited, you both will have to conclude that having a child is not such a good idea right now.

8

Accidentally pregnant: to have a child or not?

| Intensive supportive care

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In most cases, clients become pregnant unintentionally. Having sex without contraception, because of forgetfulness, because it was not available, because it is less pleasurable, because the partner did not want to use condoms: can all lead to a client getting pregnant. Pregnancy due to unsafe sex is not the best way to begin with parenthood.

What can you do?

a. Sex education

Sex education and understandable information about contraception has to be a topic of discussion with all clients. It is a good idea to find out at an early stage what a client knows about sexuality and safe sex. Does the client use contraception and is she/he able to utilize this in the proper way? Make sure that you talk with the client about the prevention of unwanted pregnancy. Go with the client to the general practitioner and discuss the most suitable form of contraception (long-lasting contraception is also possible), which reduces the risks that may accompany an impulsive decision.

b. Pregnant, what now?

If a client is pregnant, a discussion has to take place as to whether or not she wants to or is able to keep the baby. To begin with, we often see unwanted pregnancy changes the desire to keep the baby. At any rate, during the first weeks of the pregnancy when termination is still a possibility, careful consideration has to be given as to whether it is sensible to keep the baby. Do you know what the client wants? Is termination of the pregnancy an option or not?

Does religious conviction play a role in this? Often professional care workers are so shocked when they hear about a pregnancy that their nonverbal response immediately conveys disapproval. That will not help solve the problem. More often than not we see that in such situations as this, the client turns her/his back on the professional care worker and looks for answers elsewhere. Therefore, make sure that you maintain contact with the client.

With all pregnancies, a separate course of action is taken with the client, and if possible with her partner, to extensively examine to see if the pregnancy is wanted or unwanted, and what consequences it has for the future. This is an intensive process in which a new collaboration is necessary between professional care worker, manager, (educational) psychologist, doctor and perhaps other care workers.

Try to find out if the client actually can or cannot take care of her child. Do not only investigate that just for the time that the child is a baby, also talk about the years to follow (toddler, pre-school, primary school, adolescence).

From the beginning, it is important to involve the client's own social network as much as possible. If the pregnancy is not be terminated, then the network often plays a major role in the support for parenting. Even if the pregnancy is terminated, support from the client's own social network is indispensable. Whether the pregnancy is carried to full term or terminated, it is clear that the client needs intensive supportive care.

c. Termination of a pregnancy

The termination of a pregnancy occurs by way of an abortion. This is usually carried out in a specialized clinic, in compliance with the legal obligatory waiting period of five days. In most abortion clinics in the Netherlands, a pregnancy can be terminated on an outpatient basis up until thirteen weeks of the pregnancy. In some clinics, it is possible to terminate a pregnancy up to a period of seventeen weeks. Only in a small number of clinics can a pregnancy be terminated up to the twenty-second week. Consult your local legislative policy relating to the specifics in your region.

An abortion will be a topic of discussion or not depending on the policy and the background of an organization. This also applies to the professional personal care worker. Not everyone is able to stand behind the idea of an abortion.

The first thing you must be aware of as a professional care worker, is how your own values and standards play a role in this. If it is an emotionally loaded topic for you personally or if you are against abortion, for example because of your own religious convictions, then you must discuss this with you manager in a timely manner. A colleague can then take over the care of this client.

d. Going through with the pregnancy and the preparation for parenthood

If the choice is made to carry the pregnancy full term, or if it is no longer possible to make a decision otherwise, intensive family guidance is put into place. This usually occurs in combination with other forms of support to prepare the expectant mother, or the expectant couple as best as possible, for the birth and the parenthood that follows. Always try to work closely with the client's social network.

These are a few of the things that now need to be arranged: tending to the mother's health during the pregnancy, practical preparations for the birth, getting a layette, deciding where to give birth, making sure there is enough space in the home, making sure someone has a home, investigating what the financial consequences are.

The **Pregnancy book** can be used to provide information about the course of the pregnancy.

At an increasing rate for the past few years, women/parents with an intellectual disability who are pregnant for the first time, or already have one or more children, have been appealing to healthcare organizations.

It is then the social responsibility of an organization to find the best possible form of support, also in the interest of the (unborn) child.

Over the course of time there has been a substantial amount of experience acquired with regard to the supportive care of pregnant women and parents who have an intellectual disability.

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Over the course of time there has been a substantial amount of experience acquired with regard to the supportive care of pregnant women and parents who have an intellectual disability. For a number of years now, ASVZ has also had special Parent-Child provisions, where mothers/parents live with their child(ren) in their own apartment. Each mother has a professional personal care worker, and in the building there is 24-hour supportive care present which they can fall back on if needed.

Expectant mothers are also admitted into this project. They receive the necessary supportive care during the entire pregnancy, the birth and the preparations for parenthood. Needless to say, as much collaboration as possible is sought after through the mainstream provisions for (future) parents: care during pregnancy, postnatal care, health center.

9

And when the child is there...

Raising a child can be shared with other people: professional care workers, someone from the client's social network, or a combination thereof.

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In a limited number of cases, an intensive supportive care strategy still resulted in the client deciding to give the child up. More commonly, however, in these cases the client was already pregnant to the point at which it could no longer be terminated. Or it was such that the client consciously decided herself to have the child. A substantial investment in the preparation of parenthood will then be needed. You become a mother or a father by having a child. Parenting is something you have to learn and one is better able to do that than the other. And one is more capable at certain things than the other is.

Over the course of time we have seen a variety of good examples of parenting by people with an intellectual disability. These are the parents who are prepared to request support and who accept advice. They have a supportive social network and have received good methodical parenting support. Raising a child can be shared with other people: professional care workers, someone from the client's social network, or a combination thereof.

Good parenting is reflected in the well-being of the child. If the child looks happy and the development is progressing successfully, then we will also have fewer doubts about the parents' competencies.

What can you do?

Family supportive care and parenthood supportive care in families with one or two parents with an intellectual disability can take various forms: family supportive care (provision of information about a task and taking over a task from parents), supportive care for living independently, practical remedial education regarding family supportive care, Early Intervention (early stimulation of a child in the family and building a good attachment relationship), video-home training sessions, intensive family supportive care, Parent-Child provisions (24-hour residency).

The commitment and intensity of the support is determined by several factors. Accordingly, there are families with an excellent supportive social network of parents and family members. The intensity of health and welfare services is less when intensive collaboration with this network can be accomplished.

A supportive partner, who might not be intellectually disabled, can also be a protective factor. In actuality however, what we see instead is that the partner abandons the idea. There are also many multi-problem families that, along with the problems of parenting, also have other problems such as debt, addiction, or psychiatric problems.

As health and social care provider, you are also obligated to provide assistance with these problems. Usually intensive family supportive care is put in place in these families for a period of anywhere between six months to two years. A professional family care worker comes to the family several times a week to work with the family in a methodical way, under the supervision of a (educational) psychologist. There are often other types of support along with this. Additional diagnostics and/or treatment are also needed sometimes.

The care provision is focused on the family. That means that all family members are involved in it. Professional care workers are skilled in a variety of parenting and supportive care programs. Resources can be employed from video-home training sessions or video-interactive supportive care. All forms of support and supportive care do not attend exclusively to the safety and development of the child and on parenting. The well-being of the parents/mother are also taken into consideration. In certain cases, a form of behavioral therapy may be beneficial. For example, if there are problems in a relationship or when one of the parents is being severely abused or battered.

10

Parenthood in situations that are too risky

The supportive care focuses on learning how to deal with lack of understanding, anger and sadness.

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What can you do when a client still chooses to have a child while the indication is that it would be a very big mistake? What do you do when a client already has a child, is pregnant again, and the expectation is that she will be unable to care for a family of two children, which would lead to irresponsible parenthood?

Legally, you are unable to do anything. Mandatory actions can only be carried out by the authority of the court and currently in the Netherlands there is no legislation that permits mandatory actions.

Specific supportive care procedures are put into place in families where the parents make known that they would like to have another child. Experiences with the parenting of the other child could serve as an example. The client's desire is taken seriously, without judgment, and is followed by another assessment process beginning with: what do you need now to raise this child too? What do you have to do and what do you have to learn? Will you be successful? If incompetence is apparent, discouragement should certainly be the line of policy.

Parenthood with apparent incompetence

With apparent incompetence that involves danger to the child or a threat of damage to the child, attempts are made to share child custody in consultation with the parents. This is sometimes possible within the client's own family or social network, such that a reported complaint is not always necessary.

In most cases, a complaint should be reported at the Center for Advice and Reporting of Child Abuse (AMK), which can lead to a referral to the Child Care and Protection Board. A judge can impose upon the parents a Placement Under Supervision order (OTS) for the child. This means that child custody must be shared with a supervision officer. The judge can then impose mandatory health and social services. There are consequences if the parents do not accept the mandatory health and social services: they may no longer raise their child by themselves.

When the decision is made (after a youth counsel assessment and the judge's verdict) that parents are losing custody and the child must live elsewhere, it is important to teach the parents how to be parents from a distance. They will always be the parents. They can be supported with how to prepare for visits, in compliance with how they are settled in the visitation arrangements. Provide parents guidelines regarding how they can spend the time together when the child comes for a visit, for example.

When a child is taken from the parents' daily life, there can be an enormous whole left behind. Just as it is with choosing to give up a child, there is often a grieving process. There may be intense incomprehension and feelings of anger and sorrow. The supportive care is then focused on learning how to deal with these feelings, regaining balance, and finding other ways of giving meaning to the client's life. Proceeding this way can perhaps prevent the parents from compensating by deciding once again to have another child.

11

In conclusion

Information

In discussion

Support

Responding appropriately

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It is indisputable that the topic of the desire to have a child and parenthood by people with an intellectual disability amounts to a lot. In this handbook we wanted to provide an impression of the kinds of things we come across in daily practice. These practical experiences and data from research indicate that there are many risk factors, however, there are also examples of successful parenting provided there is enough support.

That is why we are strongly committed to engaging in discussion with the client in a timely manner. What we want is to inform them as best as possible about the consequences of their desire to have a child and what parenthood involves. Additionally, we want to avoid the occurrence of an emotionally loaded decision being made without having taken things into consideration, which would cause a major burden for themselves and their social environment in their often already complex lives.

This is not an easy assignment. That is why we hope The Toolkit: 'Talking about children' serves as a useful guide for others who are confronted with this dilemma. What we mainly strive for is to generate a process of raising awareness for all those involved (clients, parents, professional care workers).

We are well aware that reality is much more capricious than we have described here. Not only are people with an intellectual disability very different from each other. Often as a professional care worker you are faced with a *fait accompli* that a client is already pregnant and does not always wind up in the most optimal circumstances. It is exactly in those situations that a suitable response is needed to the presenting problem whether or not it was presented explicitly. You have to be prepared for this.

Let us know

Of course, we are open to suggestions and recommendations with regard to working with this toolkit in actual practice. Please send us your experiences and tips. We will progress a bit more if we do this collectively.

Contents of The Toolkit

1. The handbook 'Talking about children'
2. Thematic sessions: 'Wanting to have a child: looking at options'
3. The game 'Viewpoint on viewpoint'
4. 'What I wish' card game
5. 'Talking about your desire to have a child' (exercise material for having discussions with clients)
6. 'Who's there to support you?' (overview of networks)
7. 'Do I know what that involves?' (work package for clients and professional care workers)
8. Information folder 'My child wants a child...'
9. Pregnancy book

Further information

This handbook contains information about the diverse aspects of the desire to have a child and parenthood by people with an intellectual disability. There is much information that can be found on the Internet.

www.realityworks.com

Information and order site for a real care baby doll.

Colophon

The Toolkit: 'Talking about children' was developed based on a compilation of experiences of:

Clients
 Parents
 Professional care workers
 Managers
 (Educational) psychologists
 Pedagogical staff members
 Doctors

The Toolkit

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 Publication: 2008/2009

Toolkit (web version)

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 Website: Einder Communicate / ASVZ
 Publication: 2012

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Please keep us abreast of your experiences using this material.

We would greatly appreciate any tips and suggestions you may have for the improvement of this material!

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