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Barriers and Facilitators in Reaching and Supporting Parents with Intellectual Disabilities

Maroesjka Van Nieuwenhuijzen [1,2,*], Sanna Koet [1] and Marcia Lever [3]

[1] Expect Jeugd, Partners voor Jeugd, Paasheuvelweg 9, 1105 BE Amsterdam, The Netherlands; sanna.koet@hotmail.com
[2] Research Institute Child Development and Education, University of Amsterdam, Nieuwe Achtergracht 127, 1018 WS Amsterdam, The Netherlands
[3] TOP Groep, Voltastraat 33, 6902 PT Zevenaar, The Netherlands; marcia@waardanook.nl
* Correspondence: mvnieuwenhuijzen@pvj.nl

Abstract: Support of parents with intellectual disabilities should be long-term and start as early as possible. They, however, often come only into view late. The aim of the present study was to examine the barriers and facilitators in reaching and supporting parents with intellectual disabilities and young children in the Netherlands. Fourteen professionals, three volunteers, and three mothers with intellectual disabilities participated in four focus groups. Results revealed four themes: (1) improve professional development, (2) mutual professional/parent distrust, (3) strengthen support network systems, and (4) improve child welfare system responses. Professionals and policymakers lack knowledge of parents with intellectual disabilities and skills to build trust and support them adequately. Professional development is warranted. The informal network and involvement of fathers is limited and, thus, could be increased. Finally, the way the system is organized impedes adequate support. Long-term involvement and, thus, a different use of resources is needed. Reaching parents with intellectual disabilities as early as possible is important but challenging due to multiple interacting factors. Integral actions at multiple levels are essential to improve preventive care for these parents.

Keywords: barriers and facilitators; parents with intellectual disabilities; reaching; support; professionals' views

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1. Introduction

According to the United Nations Convention on the Rights of the Child [1], all children have the right to a healthy and safe development and upbringing. Children of parents with intellectual disabilities, however, face heightened risks of poorer psychosocial development, such as mental health problems, school dropouts, social problems, addiction, and delinquency [2–4]. Parents with intellectual disabilities are characterized by limitations in cognitive and adaptive functioning [5] and often face a cumulation of additional complex problems, such as traumatic experiences in their youth, psychiatric problems, and poverty [6,7]. This cumulation of risks may lead to unsafe parenting, such as inconsistency, low sensitivity, and even neglect or abuse [6,8,9]. Nevertheless, parents with intellectual disabilities are capable of raising their children, if they are adequately supported (e.g., [2,10]). According to the European Convention on Human Rights and the United Nations Convention on the Rights of Persons with Disabilities, parents with intellectual disabilities have the right to start a family and have children [11,12]. In addition, article 23 of the UNCRPD explicitly describes that "states parties shall render appropriate assistance to persons with

disabilities in the performance of their child-rearing responsibilities" [13]. However, adequate support and interventions for parents with intellectual disabilities are scarce [14]. Unfortunately, support is often crisis-driven, and parenting problems are addressed only after escalation due to the set-up of child welfare systems and lack of finances and sometimes due to systemic issues and/or barriers [15,16]. As a consequence, children of parents with intellectual disabilities are overrepresented in youth protection services [6,17–19]. From previous studies, it is known that long-term, continuous, and home-based interventions are key elements in effective support for parents with intellectual disabilities [10,20,21]. In addition, as persons with intellectual disabilities and family types vary, it is important to adjust support to the specific needs of families. It is highly important to reach parents with intellectual disabilities with young children as early as possible, even before the birth of the first child. Preventive support reduces the chances of problems spiraling out of control. However, it is hard to come into contact with these parents as they are not likely to ask for help with parenting problems [22]. Therefore, it is important to examine how professionals can reach parents with intellectual disabilities with young children and support them as early as possible. With this knowledge, policies and methods can be developed for (local) governments and professionals to support parents with intellectual disabilities.

To reach parents with intellectual disabilities and young children as early as possible, first of all, professionals in prenatal, maternal, and child care should be able to identify these families. Unfortunately, not all professionals seem to have the appropriate knowledge. General practitioners, for example, have problems with identifying and supporting people with intellectual disabilities. They feel uncomfortable providing care to them [23–25] because they often lack adequate knowledge of the characteristics and needs of people and parents with intellectual disabilities [25] and of specific treatment and tools [26–28]. Also, professionals working in midwifery, social work, and even community learning disability teams may experience problems in identifying and reaching parents with intellectual disabilities [29].

To adequately support parents with intellectual disabilities and their young children, mutual trust is crucial. People with intellectual disabilities often distrust professionals and the care system [30]. Pregnant women with intellectual disabilities fear that professionals do not approve of their pregnancy and place their child out of the home right after birth [31–33]. These fears seem to impact whether or not the parents ask for help from and work with professionals. Professionals, on the other hand, often misread these fears and interpret the attitude of the (expecting) parents as resistance to help and support [34]. Thus, to offer adequate support, professionals first have to establish a relationship of trust, which can only come into existence through mutual understanding and a good working alliance between professionals and parents [21,35,36].

Next to professional support, a supportive network of the parents is crucial. A supportive network can assist in taking care of practical issues and helping to raise the children, thereby decreasing stress for the parents. However, the network of parents with intellectual disabilities is not always supportive [37–39]. Therefore, adequate support also includes strengthening the supportive network of the parents [36,40–42], as crucial factors for successful support are cooperation between parents, their informal network, and professionals [43,44].

Despite the fact that we have come to better understand the facilitating factors in reaching and the supporting needs of parents with intellectual disabilities, it still appears to be difficult to implement those in practice and offer adequate support. Ample qualitative studies on the experiences of a variety of professionals working with people with intellectual disabilities revealed working with parents with intellectual disabilities is challenging [30,45–47]. Professionals lack experience, knowledge, and attitudes with regard

to parenting with intellectual disabilities. In addition, adequate and timely support for parents with mild intellectual disabilities and financial resources are lacking, as well as communication and cooperation between all professionals involved. Professionals struggle with the power imbalance between the professional and parent, parents distrusting the system, the conflicting priorities of parents and children, and the personal emotional impact. Several studies reported requirements for adequate support being the following: (1) training of professionals, (2) more time for professionals to support parents with intellectual disabilities, (3) addressing contextual problems and promoting self-efficacy, (4) more accessible information for parents, and that (5) the formal and informal network of mothers should work together [30,46,48,49]. As social service systems differ between countries, the results of these studies cannot be generalized to every country. Thus far, information is lacking on barriers and facilitators in reaching and supporting parents with intellectual disabilities with young children as early as possible in the Dutch context. The present study therefore aims to fill in this research knowledge gap. The research question is "What are barriers and facilitators in reaching and supporting parents with intellectual disabilities with young children in the Netherlands?".

2. Materials and Methods

2.1. Design

This study is of a qualitative and inclusive nature and conducted by researchers and program developers who are all specialized in working with parents with intellectual disabilities. Inclusive research is a way that people with intellectual disability and other researchers can learn from each other and work as a team [50]. When inclusive research is done well, the researcher with an intellectual disability brings skills and ideas to the research process that only they can bring [51]. Having a coresearcher with intellectual disability can have benefits such as helping to deepen discussion about important themes, helping participants with intellectual disability feel more comfortable and willing to open up, and making sure that the research is reported in an accessible way [52].

Therefore, a lived experience expert was part of the research team. She is a mother with intellectual disabilities with two children, aged 11 and 14 and has received support from several agencies throughout the course of her life. She fulfilled a role as an advisor in the preparation of focus groups and assisted with data collection to create a safe environment for the other parents and interpret results. Her reflections on the focus groups were relevant and added to the outcomes of the focus groups and are therefore used as additional results. In addition, an advisory board, including an expert on parenting support for parents with intellectual disabilities, was established.

2.2. Participants

Three mothers with diagnosed intellectual disabilities, fourteen professionals providing formal support, and three volunteers providing informal support participated. All mothers lived in an urban region in the west of the Netherlands. They all had mild intellectual disabilities and received support from a specialized social service organization that supported people with intellectual disabilities at the time of the study. The support consisted of at least family and parenting support according to the methodology HoldOn, which was developed for parents with intellectual disabilities [53]. Participant 1 was a mother of 36 years of age, no migration background, and three children (aged 10, 7, and 4). She was single, lived with her children, and had no job. Participant 2 was a mother of 33 years old with a migration background and two children (aged 2.5 and 3 months). She lived with her partner and children in a location of a support service organization and had no job. Participant 3 was a mother of 29 years old with a migration background and one

child (aged 2.5). She was single, lived with her child, mother, and grandmother, and had no job.

Participating professionals and volunteers worked in different social services in the Netherlands (see Table 1). All the professionals and volunteers were females of varying ages and numbers of years working with parents with intellectual disabilities.

Table 1. Professional background of professionals and volunteers.

Support		Organization	Respondents
Formal support	Social services for youth care	Municipality	6
	Specialistic support for parents with intellectual disabilities	Support provider	5
Informal support	Matching volunteers to families in their own neighborhood	Informal support provider	3
Volunteers	Supporting parents who need extra help with parenting		3

2.3. Data Collection

Data were collected through four focus group sessions in 2022; one with mothers and three with a combination of professionals and volunteers. Separate guidelines were prepared by the research team and with input from the advisory board. To ensure that mothers understood the expectations and questions in the focus group, materials were discussed and developed with the lived experienced expert and with the advisory board in advance. The focus group for mothers was prepared by interviewing and filming the lived experience expert. The lived experiential expert also joined the focus group and was introduced as our co-researcher. With her presence and story on film, we intended to put mothers at ease and to stimulate them to share their experiences. The focus group was led by two facilitators and started with an explanation of the goal of the focus group and an introduction round. Mothers were asked five questions throughout the focus group: who helped you with parenting, who gave you stress, what was helpful (what were the pleasant moments), what was not helpful (what was heavy), and what were your needs? To promote the recollection of situations and actors in these exciting years and to help structure the discussion, we presented parenting in four phases (pregnancy, post-natal, baby, and toddler). Then, the five questions were asked for each of these phases. To give mothers an example and to facilitate the discussion, for each phase, we first presented a video fragment of the interview with the lived experience expert, with her permission, in which she responded to the questions. In the focus group, she added some information to the interview. In addition, posters with pictures were used as visual aids to help mothers focus on the phase and topic at hand. At the end of the meeting, mothers were asked what their suggestions were for parents and professionals in reaching parents with intellectual disabilities.

Three online focus groups were organized for professionals and volunteers in TEAMS. Professionals from different organizations and volunteers were equally divided over the three focus groups. Thus, each focus group included professionals from the municipality, the support provider, the informal support provider, and a volunteer. The focus groups were led by two facilitators and started with an explanation of the goal and the use of the online whiteboard (Miro) and an introduction round. To improve inclusivity and diversity of perspectives, participants were asked to use online post-its to write down their ideas on what helps and what is difficult in reaching and supporting parents with intellectual disabilities during four phases in early childhood (prenatal, post-natal, baby, and toddler).

Next, participants were asked to read others' ideas and, when needed, add post-its. Finally, the ideas were discussed in the group.

2.4. Procedure

The study design was approved by the Ethics Review Board of the Faculty of Social and Behavioural Sciences, University of Amsterdam (number 2022-CDE-14368). The goal was to recruit six parents, three volunteers, and fifteen professionals. Mothers were recruited through one participating organization specialized in care for people with intellectual disabilities. Inclusion criteria were as follows: (1) the participant or their partner has a suspected or diagnosed mild intellectual disability, (2) the family receives support for a minimal period of 6 months, and (3) at least one of the children is under the age of six years old. A professional appointed in the organization repeatedly contacted all her colleagues and team leaders. Sixteen parents were contacted, of which six agreed to participate. However, three parents were no longer available due to problems or lack of time. Professionals and people offering informal support were recruited through participating organizations and were selected on the criteria of having experience in working with parents with intellectual disabilities. One professional was sick the day the focus group was organized. All the participants were given written and verbal information about the study and its aim. A consent and confidentiality form was produced in an easy-read and clear format in order for all participants to fully understand the scope and aim of the research. The participating mothers were again informed at the onset of the focus group to ensure they fully comprehended the purpose of the session and were reminded that participation was voluntary, consent could be withdrawn at any stage, and how anonymity would be ensured. They all signed the form on-site at the onset of the session.

The focus group with mothers was held at a location provided by a partner organization. All participants were familiar with the location and came on their own. One of the participants brought one of her children, for whom a nanny was available during the session. All focus groups were led by the same two facilitators and lasted about two hours, including a short break. Parents received EUR 25 in the form of a gift card of choice and travel expenses. The lived experience expert received a gift card of her choice of EUR 25 an hour. The organization of the participating professionals received compensation on the basis of hourly wages.

2.5. Analyses

Credibility and validity of the results with limited effect of research bias were ensured by investigator triangulation in three steps. First, each facilitator of the sessions wrote a summary of all sessions separately, which they discussed. Then, they combined this into an overall summary with highlights from the four sessions. Second, the first reading of these findings was discussed with the lived experience expert by the second and third authors in two separate meetings. In the first session, the focus group with mothers was discussed. She was asked what stood out in the stories of the mothers, what went well in their motherhood, what went less well for which they needed support, and finally, whether she agreed with the preliminary findings of the research team. In a second meeting, she was asked to reflect on the preliminary findings of both mothers' and professionals' discussions in the focus groups. The reflections of the lived experience expert were included in the Results section (Section 3).

Third, audio recordings were made of all focus groups, and the transcripts and reflection meetings with the lived experience expert were coded by the first author and analyzed by the research team [54–56]. Deductive coding was used according to the topics of the focus groups with professionals (reaching and supporting (anticipating and strengthening

protective factors) parents), derived from the literature on success factors in supporting parents with intellectual disabilities [10,29,42]. First, 386 codes (245 to barriers; 141 to facilitators) were assigned to transcripts from text from the online whiteboard and the discussion in the focus groups by the first author. The codes were clustered by topic (reaching and supporting) by the first author, but as there was a lot of overlap, we decided to integrate them. Inductive coding in several rounds, in which different codes were clustered into categories by the first author, resulted in 28 categories, which were discussed with the research team. These were clustered into 8 themes (families not in the picture, professional/network, service system, knowledge parents, characteristics ID, distrust parents, lack of supportive network, and lack of collaboration) by the first author. In a final round, these 8 themes were discussed with the research team and compared to the summary of the findings. Several categories were assigned to a different theme, and themes were clustered further, resulting in 4 final themes (improve professional development, mutual professional/parent distrust, strengthen support network systems, and improve child welfare system responses), with 22 subthemes. As the facilitators were linked to the barriers, codes of the facilitators were assigned to these 22 subthemes, resulting in 16 subthemes of facilitators. The focus group with the mothers was analyzed similarly. The topics were as follows: who was helpful and who was not, what was helpful and what was not, and what were mothers' needs. In total, 96 codes were assigned to the transcripts. These codes were clustered into 3 categories of barriers (fathers, family members, and distrust) and 4 categories of facilitators (receiving support, fathers, not having to ask for support, and working alliance). Because only three mothers participated, and there was overlap with the themes from the professionals, we decided to integrate these themes with those of the professionals (see Table 2 for themes and subthemes).

Table 2. Themes and subthemes.

Themes	Barriers	Facilitators
Improve professional development	• Families not in the picture • Lack of knowledge about intellectual disabilities and context problems • Lack of skills to support people with intellectual disabilities • Attitude • Lack of knowledge about available support	• Early recognition in pre- and post-natal and preventive care and schools • Education for professionals • Training in skills and attitude • Intervision
Mutual professional/ parent distrust	• Distrust professionals • Not asking for help • Not sharing information • Experiences of failure • Shame • Fear of stigma • Professionals' fears	• Transparency • Sharing positive experiences • Build on trust relationship • Easily accessible support

Table 2. *Cont.*

Themes	Barriers	Facilitators
Strengthen support network systems	• Loneliness • Small and not supportive informal network • Society has no time to volunteer • Parents distrust others	• Building informal network • Involve fathers • Organize volunteer support
Improve child welfare system responses	• Lack of time and finances • Varying visions by policymakers • Lack of appropriate support • No access to support • Lack of professionals and high turnover • Lack of collaboration between organizations	• Communication with and training for government and policymakers • Preventive support • Long-term support • Easily accessible support • Network consultation, including informal support organizations

3. Results

Analyses of the qualitative data of the focus groups show four themes concerning barriers in reaching and supporting parents with intellectual disabilities: (1) improve professional development, (2) mutual professional/parent distrust, (3) strengthen support network systems, and (4) improve child welfare system responses.

3.1. Theme 1: Improve Professional Development

3.1.1. Barriers

Professionals mentioned the disabilities and needs of the parents are not seen or considered by the professionals, especially their colleagues in pre- and post-natal, and preventive care lack the knowledge and recognition of the characteristics of parents with intellectual disabilities and the challenges they face.

> "*Not all professionals know how to deal with parents with intellectual disabilities, cannot spot it, and also ask too much of a family*" (Focus group professionals, #1).

Concerning support, it was mentioned that many post-natal and preventive care professionals lack the skills to communicate and work with parents with intellectual disabilities to adjust to their needs and gain their trust.

> "*Professionals are always so inclined to talk and talk and talk, but parents with intellectual disabilities check out, after a few minutes*" (Focus group professionals, #3).

In addition, it was mentioned that many professionals lack the appropriate attitude, such as being vulnerable, transparent, and persistent, practicing self-reflection, collaborating with parents, and having a growth mindset (i.e., believing in the parents' capacity to change and develop). Even many (experienced) professionals still have negative attributions about parents with intellectual disabilities.

> "*It is thought too quickly that parents with intellectual disabilities have no developmental potential, especially with a young child*" (Focus group professionals, #3).

Moreover, professionals find it hard to support parents with intellectual disabilities, as "they cannot oversee their situation because of their intellectual disability", multiple problems in their family, and multiple involved professionals. Professionals struggle to cope with parents who, in their view, are not always aware of or deny having intellectual disabilities and challenges. In addition, they experience barriers supporting parents who, in their opinion, lack insight and self-reflection on concerns and their capacity and parents who are overconfident and think they can manage without support.

> "*Parents do not see concerns, [and] cannot oversee the consequences of problems*" (Focus group professionals, #2).

Furthermore, according to the professionals, they lack knowledge of the available services for parents with intellectual disabilities.

3.1.2. Facilitators

The professionals indicated that professionals in post-natal, infant, and child care are best suited to recognize parents with intellectual disabilities early on and refer them to support services.

> "*I'm sure that when midwives, general practitioners and preschool teachers know how to signal an intellectual disability, together we can develop a support plan earlier. Prevent larger problems. And think earlier of how to support this parent in parenting their child, with small steps and small interventions*" (Focus group professionals, #3).

According to the professionals and lived experience experts, and also professionals in youth care, municipalities, debt and housing services, and schools should be educated on the parents with intellectual disabilities, how to work with them, where to refer to, and the available specialized support.

> "*Various care professionals need more knowledge on the challenges future parents with intellectual disabilities face. What are future important life events that may be risky, and what can professionals do to support parents?*" (Focus group professionals, #1).

> "*I think that we have to look broader than just youth (health) care to signal [parents with intellectual disabilities] earlier. These familys obviously encounter more problems in different domains*" (Focus group professionals, #3).

3.2. Theme 2: Mutual Professional/Parent Distrust

3.2.1. Barriers

An important barrier concerning both reaching and supporting parents with intellectual disabilities, in the view of professionals, is that parents often distrust professionals and are, therefore, reluctant to seek and accept help or share information.

> "*Mother only apps me when she wants something from me, but then she is always resistant, because she thinks I have an opinion on everything*" (Focus group professionals, #1).

According to professionals, there are several explanatory factors. First, negative previous experiences with support and unrealistic goals set by professionals have decreased the self-confidence of parents and trust in professionals and the positive contribution of support to their lives.

> "*If you are constantly rejected by debt support services or they don't keep appointments, or it is made so big, then one gets tired of support. It doesn't work. They don't understand me, or, being disappointed in oneself, and not having the self-confidence. That's an important subject. Self-confidence or belief in own competence. That is being taken away, because they do not know their way [in child welfare system] or are being rejected*" (Focus group professionals, #3).

Second, professionals mentioned parents are ashamed, in denial of their disabilities and challenges, and want or think they need to prove that they can do it themselves.

> "*Maybe they do want help, but there is mostly a lot of fear, and you see that very often with other cultures, right. You don't hang out your dirty laundry, no external help, and you solve your problems yourself, and there is quite a bit, well yes, fear and resistance*" (Focus group professionals, #3).

Third, according to professionals, parents fear stigmatization, attributions such as "parents with intellectual disabilities cannot parent" and "parents with intellectual disabilities are unmotivated and reject help", and out-of-home placement of their child.

> "*I think fear, and also distrust, also does come from that fear that youth care is involved. I can lose my children. My children can be taken out-of-home just like that, because professionals are watching*" (Focus group professionals, #2).

Indeed, mothers mentioned they found it difficult to ask for and accept help because they were skeptical of the support offered and because they distrusted not only professionals but also family members. They feared interference.

> "*. . . that people come to your home thinking they know better, especially with your first [child]. Then you try it yourself, but then you don't get the chance*" (Mother 2).

Professionals struggle with the balance between the interests of the child and the needs and wishes of the parents. They indicated they sometimes do not trust the parents' parenting skills and, therefore, fear the safety of the child. They feel the pressure of not taking risks when considering the well-being of the child. At the same time, they are afraid to lose the trust of parents by discussing this with the parents.

> "*Discussing difficult things is sometimes complicated, because it might be at the expense of the relationship you just built*" (Focus group professionals, #2).

Therefore, they often hesitate to be open and strict with parents and to scale up to more intensive support or youth protection services.

3.2.2. Facilitators

With regard to reaching and supporting parents, both the professionals and the lived experience expert indicated that young parents with intellectual disabilities are influenced by negative stories about youth care professionals on (social) media.

> "*I think it is because of the media; often videos go viral of a child being removed from their parents, so in social media often those kind of things are said. . .Parents scare each other, and are often more negative [about professionals]*" (Lived experience expert).

Therefore, they suggest professionals could better explain what their task is, what support they offer, and what the roles and tasks are of other professionals, thus being transparent about expectations and the limits of each professional role.

> "*[It is important] to be transparant and clear, and give them the feeling of trust. That is very important for parents with intellectual disabilities. And to stay involved for a longer periode of time*" (Focus group professionals, #3).

Moreover, distrust can be reduced when success stories and (positive) experiences are shared by and with parents via social media, parent meetings, or other platforms.

> "*Parents' experiences with support may help other parents to reduce their fear for professionals*" (Focus group professionals, #3).

Mothers themselves and the lived experience expert mentioned trust can be built by spending time on building the relationship, not giving up too soon, and staying involved for a long time.

> "*You have to be able to communicate with parents, else they do not trust you. [Professionals] have to prove themselves, that they are open to help parents, that they support them*" (Mother 1).

Professionals could also help parents formulate their needs for support and set realistic goals together with the parents in order to prevent parents from failing and feeling insecure.

> "*Professionals expect too much from the mothers that they should immediately ask for help themselves. They always want to hear that: 'What is your request for help?'. But you can't expect parents with low IQs to indicate that themselves. Surely professionals first just need to come more often and build a bond, because parents have so few people around them*" (Lived experience expert).

In addition, mothers mentioned professionals could not only focus on what goes wrong but also on what goes well and give parents time to try on their own.

> "*Professionals act as if they know it all better. They come and tell you what you have to do, whereas you try to do it your self and want to learn. You want to think about their advise and act at your own pace. You have to be able to do it yourself"* (Mother 2).

Professionals suggested that professionals could use adequate communication, recognize mutual fears and discuss them with parents, and ask what parents need to increase their trust and take away their fears.

> "*I work with a parent who says 'I distrust everyone'. The other day, I said to her 'I think you secretely like me'. She had to laugh. One can better discuss it [distrust and fear], and [recognize] that parents find it difficult that a lot of professionals visit their home and have an opinion about everything*" (Focus group professionals, #2).

According to the lived experience expert, parents themselves could be open for help and need someone who has (a positive) experience with professional support to promote, help, and stimulate them to seek professional support. In addition, she suggested that in order to decrease insecurity and normalize help-seeking behavior, parents could be informed about the challenges of each individual phase of child development and that it is completely normal to struggle with parenting. Easily accessible help and information could be made available, as well as opportunities to meet other parents to exchange experiences and tips on parenting.

> "*[It would help if parents have] more contact with [other parents] who talk positively about professionals. That they hear it often, and from others with whom it went well*" (Lived experience expert).

3.3. Theme 3: Strengthen Support Network Systems

3.3.1. Barriers

According to professionals and the lived experience expert, parents with intellectual disabilities experience a great sense of loneliness and feel they have to parent on their own. They often lack a supportive network, and people around them lack time to offer structural informal support. Indeed, no one or only a few persons were mentioned by the mothers from either the formal or the family network who were supportive in the pre- and post-natal period. During major events, especially during the baby period, mothers felt support from family members and professionals was lacking, which caused stress and feelings of loneliness in raising their children. Fathers were often absent. When present,

they were experienced as unsupportive or worse, causing (additional) stress in all three mothers. Their pregnancy and the baby were not always accepted by fathers and family members and they often argued with the father, asking him to help in the household or with parenting tasks.

> "*[The most stress was caused by] arguments [with father]. And his mother, who also tried to talk me out of, yes, to have it taken away. Because we were living in a room. They didn't accept it. I still was together with the father, but pregnancy we could not share. I was on my own*" (Mother 1).

> "*After my pregnancy he said to my sister and brother in law that he did not recognized the child. . . I had always problems with the father, and fights. That's what caused stress*" (Mother 3).

One mother indicated that she would like to get more support from the father in order to relieve her burden.

> "*[It would have helped] if he had done more in the house, housekeeping, and grocery shopping. If he hadn't, then from my family*" (Mother 1).

Next to their parents' own network, support can be found in the informal network of voluntary support. Professionals indicated that the power of this (potential) informal network, such as neighbors or parents from school, is underestimated and often not well-mapped by professionals. At the same time, people have less time to volunteer, and when families in the neighborhood volunteer to support parents with intellectual disabilities, building a (long-term) relationship can be challenging, and volunteer families may terminate the support because of conflicts with the parents.

> "*....cause and consequence is not overlooked quickly, [and they] sometimes get into arguments. Informal network is then like: Yeah, it's nice what I've done all, and there I get a big mouth, so I'll stop. That's what I do see happening a lot*" (Focus group professionals, #2).

3.3.2. Facilitators

According to the professionals and lived experience experts, parents with intellectual disabilities need more contacts. They need help and support from a professional to encourage them to build relationships with other parents, e.g., by volunteer work or re-integrating into a job.

> "*Daytime activities are important for everyone. To stay in a rhythm. . . to have social contacts is important for everyone. Good professionals can create a network [for parents]*" (Lived experience expert).

In addition, mothers indicate they wish the father had a larger role in parenting, so the (potential) role and level of involvement of fathers should be considered, and fathers should be assisted and stimulated to fulfill their paternal role and should also be more targeted by professional support on parenting.

> "*[It would have helped] if he just had been a father to the children and he had said 'take same time for your self'*" (Mother 1).

Professionals mentioned the need to invest in a long-term informal network, such as parents from school, neighbors, parent support groups, and lived experience experts, and easily accessible support, such as walk-in hours to consult on parenting and practical help or informal tailor-made support by families in the neighborhood.

> "*It would be great if a group of parents can share experiences, to take away fears and increase trust, but also to normalise [asking for help]. To approach this group parents who are no professionals, and can help you how to cope*" (Focus group professionals, #3).

Organizations for informal support can be involved with the families and offer consultation as well.

According to the professionals, cooperation between professionals and the informal network can be improved by recognizing organizations for informal support as a relevant partner in the support of parents with intellectual disabilities.

> "*Organisation for informal support should be visible in the neighbourhood where families live who need more support*" (Focus group professionals #1).

In addition, both the lived experience expert and the professionals mentioned the need for short lines of communication between organizations and a coordinating professional who maps the support and frequently schedules network meetings with other professionals involved in the family. Professionals should exchange success stories and what works for the family.

> "*One person should be appointed who maps all the professional support and provides insight for the parent, but also for other persons involved*" (Focus group professionals #3).

3.4. Theme 4: Improve Child Welfare System Responses

3.4.1. Barriers

Professionals mentioned a lack of time and finances to work on trust and a long-term relationship with parents.

> "*Problem with providing practical help and in that way building a relationship is, we don't have the financial resources, for example, to work that way, so it has to be fast and it has to be as fast as possible. And as soon as it seems to be going okay and the goals are met, as far as possible, the support is ended, so that actually puts a kind of enormous pressure on supervisors as well*" (Focus group professionals, #1).

Resources are dependent on municipality funds and the knowledge of government officials. Because of a lack of appropriate help and long waiting lists, support starts too late, and problems often increase. In addition, when parents receive support, it is often short-term and crisis-driven due to the current system of support in the Netherlands.

In addition, parents do not always attend available services, such as consulting hours for parents with newborn babies or preschool for toddlers, as it is not compulsory. And they do not know their way around the specialized mental health or youth care services.

> "*The trouble is if parents don't go to consulting hours. How do they come into the picture? Many mothers still live with their parents, so they arrange it themselves. They come into the picture later when they want to live on their own, or if the child is older, but then a lot has already gone wrong*" (Focus group professionals, #1).

Furthermore, there is a great shortage of professionals in youth care and care for people with intellectual disabilities; staff turnover is high within the agencies, thereby losing essential knowledge and skills, and professionals cannot always be matched with the wishes and needs of parents with intellectual disabilities. Finally, according to professionals, providing adequate formal support is hard, as too many different organizations are involved with families who do not collaborate and have no short lines of communication.

> "*. . .that people are working past each other, or that actually parents get out of the picture, and then they only come back into the picture at the time there are problems in raising the baby*" (Focus group professionals, #1).

In addition, parents are reluctant to share information on their network and support previously received or to give permission to contact their network of previous professionals because they distrust professionals, which complicates the continuances of providing adequate support.

3.4.2. Facilitators

Professionals mentioned the importance of improving the knowledge of governmental officials and municipality employees about the needs of parents with intellectual disabilities in order to allocate corresponding resources. Professionals should be trusted to understand the needs of the family and allowed more autonomy to act accordingly, without being limited by boundaries set by local government and financial structures, in order to remain involved with parents with intellectual disabilities over a longer period of time to do what is right, necessary, and responsible for the family.

In order to make support more easily accessible for parents with intellectual disabilities, it was suggested to increase low thresholds and easily accessible informal support, such as prolonging post-natal care, information, and walk-in consultation hours at the children's healthcare centers, mandatory consultations, preschools, and preventive support in the neighborhood.

> "*Preventive support is needed. More support in the neighbourhood where the family feels comfortable. Or maybe [support] from schools, child day care, or midwifery*" (Focus group professionals, #1).

Support from lived experience experts and organizations who mediate between parents and volunteers should be used more often.

> "*More low key support for parents by parents is needed. For example, that school asks parents whether they can help a specific parents, or asks 'who is prepared to help other parents*" (Focus group professionals, #1).

In addition, professionals of different organizations should communicate and cooperate more and, in consultation with the parents, agree upon which service provider takes the lead.

4. Discussion

The aim of this study was to examine the barriers and facilitators in reaching and supporting parents with intellectual disabilities and young children as early as possible in the Netherlands. Four themes were distilled: (1) improve professional development, (2) mutual professional/parent distrust, (3) strengthen support network systems, and (4) improve child welfare system responses.

Results show one barrier in reaching parents with intellectual disabilities and young children being professionals in pre- and post-natal care and preventive (child) care lacking the knowledge of the characteristics and needs of people with intellectual disabilities, which is in line with and adds to earlier studies among general practitioners [25,26] and professionals in healthcare [30,57]. Parents themselves distrust professionals, the child welfare system, and even their own (family) network. Therefore, they are reluctant to ask for help and to invite and involve people in their family situation, which elaborates on previous studies [22,30–33]. Furthermore, it was found that parents with intellectual disabilities lack the knowledge of potential and available support. To reach more parents as early as possible, professionals in pre- and post-natal and preventive care could have a role in the early detection of parents with intellectual disabilities, give them more personal attention, and motivate them to seek and accept help. Therefore, their knowledge of intellectual disabilities and their needs should be developed. In addition, parents with intellectual disabilities could

be made aware that parenting is difficult for everyone and that asking for assistance with parenting issues is normal. Easily accessible and comprehensive information and support could be increased for regular questions about parenting, for instance, by exchanging experiences with other parents in similar situations. This is in line with a previous study on mothers with intellectual disabilities in mental health care [30]. Experience experts and advocacy organizations may play a role in informing parents [58–60] by providing success stories, online information, and group sessions (cf. www.bumpyroad.org.au, accessed on 10 November 2024) [61]. It should be noted that parents are often thought of as "hard to reach" by professionals. This was also found in studies with marginalized families in the school system [62,63]. They, however, were not unwilling or difficult, but schools were hard to access due to hidden expectations and potential hostility. Similarly, social services are hard to access for parents with intellectual disabilities when professionals keep thinking from their own "normal" perspective and are not adapting to the needs of parents with intellectual disabilities to make their services inclusive.

The results, however, show the problem is much broader. Even in specialized (child welfare) care, professionals lack the relevant knowledge and skills on how to build a positive working alliance, which is in line with previous research [29,30,45]. Results show professionals may have fears and feelings of distrust towards parents and internal conflicts on how to balance the safety of the child and the relationship with the parent, which was also seen in other countries [45,46]. In addition, many professionals lack the appropriate attitude regarding parenting with intellectual disabilities. Even experienced professionals working with parents with intellectual disabilities mentioned parents not being able to oversee their situation because of their intellectual disability as being a barrier to providing adequate parenting support. This is an indication that these professionals themselves seem to struggle to keep up a non-judgmental and supportive attitude. This very subtle and often unconscious attribution is found not only in professionals but also in the broader context of organizations and society [47,64–66]. Professionals may struggle with whether they can justify that the children live with parents with intellectual disabilities, as society questions the parenting skills of these parents. Obviously, this impacts professionals' views on parenting with intellectual disabilities, even during pregnancy, and makes them feel excessive pressure. The dynamic of mutual distrust between parents and professionals may feed the fears of both parties further, which obviously affects the willingness to ask for help and the working relationship.

To offer adequate support, professionals should acquire knowledge of skills and appropriate attitudes to build good working relationships with parents. Increasing confronting disablism and professional development is mostly achieved by education and contact interventions, which may yield positive results [67]. Advocacy groups and experiential experts can add experience-based knowledge to practice-based knowledge and have increasingly been used in training for professionals [68]. Another way is by using a method with a collaborative, structured behavioral approach, such as Parenting Young Children [69]. Also, peer learning in peer support groups can increase skill development by discussing and exchanging information, tips, and knowledge [70]. Adapting a relational approach, including pro-activity, flexibility, and shared responsibility for inclusion, may also decrease ableism and increase inclusive support [71].

In line with previous studies [37,38,72], results showed mothers with intellectual disabilities tend to feel lonely in raising their children because of a small existing network that is not always supportive. The informal network of parents should be increased, but professionals have a hard time doing so, possibly due to a lack of knowledge, time, and skills. They could support parents in strengthening natural community-based networks that exist for other parents, such as other parents from school, neighbors, and parent groups, and

stimulate them to start (volunteer) work and daily activities, which are important sources of resilience for people with intellectual disabilities [41,73]. An often-overlooked source of the informal network and support is the father. Although mothers may complain about their partners and the stress they cause, they long for a supportive (ex)partner who is a co-parent to share the tasks with. Research shows that, in general, (early) involvement of fathers in parenting and children's lives is important for the development of the child [74,75] and reduces stress levels in the mother [76–79]. Nevertheless, fathers with intellectual disabilities are surprisingly hardly or not at all involved in parenting support [66,80,81]. Therefore, it is important to involve fathers in parenting support from the very beginning, seeking the strengths of the paternal role but also providing support in the relationship between the parents and in how to stay the best parents, even when the relationship between partners is under pressure.

Informal support could also be increased by using organized volunteer support, such as volunteer families. In the Netherlands, there are several upcoming organizations that intermediate between families in vulnerable circumstances and informal support volunteer families in the neighborhood, who can relieve stress by helping out. Unfortunately, the strength, scope, and availability of voluntary informal support are underestimated by professionals. Professionals do not know how to find these organizations, and the match between parents and volunteer families is sometimes strained. Volunteers need to be trained to support parents with intellectual disabilities, specifically new mothers, and provide a bridge between these mothers and professionals, thereby addressing mistrust. Results also show that professionals, the informal network (both family, friends, and organized volunteer support), and parents should cooperate more, as is also suggested in previous studies in other countries [30,45].

Finally, working on better methodologies and training for professionals to support parents with intellectual disabilities will not improve the situation of the families as long as the child welfare system keeps failing. Time, finances, appropriate care, sufficiently educated professionals, a lack of collaboration between professionals, and a high turnover of professionals were mentioned as major barriers to making sure these parents receive the support they need. These barriers are of major influence on the success of support and interventions above all because they are all important in creating trust between parents and professionals, which is the primary need to actually be able to reach and give these parents the support that they need. This seems to be a general problem in the different child welfare systems internationally [29,30,45]. For the adequate support of parents with intellectual disabilities, long-term involvement with their families is needed, i.e., being present in the background and working on increasing networks and skills when the situation is stable and increasing the support when serious problems threaten to arise. Organizations providing parenting support and scholars should act together to inform policymakers about these insights and convince them to reallocate resources.

A strength of this study is that it is the first to ask professionals and mothers what works in reaching and supporting parents with intellectual disabilities in the Dutch context. Despite differences in social service systems between countries, this study revealed similar barriers and facilitators, but it also adds to previous studies. In addition, a lived experience expert participated as a co-researcher, assisting in preparing and conducting the focus groups and reflecting on the results, which has enriched the interpretation and thereby enhanced the results. Including both the experiential knowledge and the expertise of the professionals strengthens the value of the scientific results for practice [68]. Nevertheless, the results should be interpreted with care, as this study also has some limitations. First, although we have included mothers with intellectual disabilities, the sample size was very small. It is hard to find parents with intellectual disabilities who are willing and able to

participate in research, as is experienced by many researchers. Moreover, only mothers were found to participate, and not fathers. Second, intellectual disability encompasses a wide range of support needs, intellectual levels, and coexisting disabilities. This study, however, does not differentiate between those different needs and levels. Third, to stimulate exchanging experiences and for logistic purposes, focus groups were organized to get input from mothers. Although all mothers were invited and given space to share experiences, not all mothers spoke as easily in a group. Individual interviews may have yielded more input from the mothers. Fourth, information about participating professionals, such as age and number of years of working experience was lacking and hampered interpreting and generalizing the findings. Finally, the Dutch context of this study limits generalization to other countries, and more studies should be conducted in the Dutch community to strengthen the results of this present study.

By confirming and elaborating on what has been found in other countries, this study revealed that barriers and facilitators in working with parents with intellectual disabilities are similar in different countries. The study adds scientific evidence to the contextual model that explains parenting with intellectual disabilities from multiple factors [7]. It is not just the characteristics of parents but how they are seen and treated by professionals and society and how the child welfare system is set up. In addition, results showed negative attributions not only to be present in professionals not directly working with parents with intellectual disabilities, such as judges [20,82–84], but also in professionals with knowledge and experience in working with parents with intellectual disabilities. The study also provides a better understanding of mutual distrust between parents and professionals. Finally, the study revealed low recognition and support for parents with intellectual disabilities early on in the support system. This is a missed opportunity and has major (financial) consequences for both children, parents, and society. Therefore, preventive interventions are crucial, and supporting parents with intellectual disabilities should start from birth or even during pregnancy. In addition, support for parents with intellectual disabilities should move from individualized approaches to interdependent and community-based approaches.

Future research should include not only mothers but also fathers to learn about their views of involvement in parenting and their parenting role. In addition, parents with different family types and different needs should be included. Moreover, the knowledge provided by professionals, parents with intellectual disabilities, and lived experience experts should be implemented in practice by developing tools and training for professionals, and its feasibility and effects should be evaluated.

5. Conclusions

Reaching parents with intellectual disabilities as early as possible is important but challenging due to multiple interacting factors. Once reached, parents are not offered the adequate support they need. If they receive support from well-trained professionals, the system fails; professionals do not have the right resources (time and finance) to offer adequate support, and the government is not aware of what is needed. Despite knowing what is needed, it appears that we are unable to break this trend and dynamic of interacting barriers. As a result, parents with intellectual disabilities are still not getting the support they are entitled to, and new generations continue to grow up in preventable situations. Thus, drastic and integral actions at multiple levels are crucial to improve preventive care for these families.

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