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# Experiences of Working with Parents with Mental Disabilities in Private Education Institutions: A Qualitative Focus Group Study

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#### Abstract

The purpose of this study is to understand the experiences of parents with intellectual disabilities employees whom working in official private education institutions and the contribution to the scientific field. A qualitative method was used in this research. The study adopted a phenomenological design, highlighting the exploratory nature of qualitative research. Six focus groups were formed in this study. These six focus group sessions were conducted, with total of 36 participants. Coding analyses were done using the MAXQDA 2022 program. Then, content analyses from the focus groups were conducted focusing to answer the research questions. This study recommended that counseling services should be provided specifically to intellectually disabled parents, focusing particularly specific on the social work profession. In addition, this study recommended for competent authorities to conduct further close monitoring and case follow-ups for involved families to observe the ongoing situations between parents and children.

# INTRODUCTION

The concept of having an intellectual disability insufficiency refers to a disability characterized by significant limitations in both intellectual functioning and in many daily life aspects such conceptual, social, and practical adaptive skills (American Association on Intellectual and Developmental Disabilities [AAIDD], 2019, n.d.). The lack of these skills can lead to difficulties in social adaptation for individuals with intellectual disabilities (Gusmão, et al., 2019).

To establish a decent family dynamic in taking care of individuals with disabilities, is considered a fundamental human right and is accepted as normal, after adapting to social life. However, literature indicates some challenges associated with individuals with intellectual disabilities in the process of establishing families, dealing with their children, and fulfilling the other

family responsibilities. Family members, guardians, doctors, psychologists, and social workers experience many difficulties and ethical dilemmas concerning parenting style that taking care of individuals with intellectual disabilities (McConnell, et al., 2005). Research often finds that individuals with intellectual disabilities who have children face enourmous challenges during their children's developmental stages and may neglect supposedly actions in the best interest of the child (Collings & Llewellyn 2012). Additionally, studies indicated a link between low social-emotional development in children and mothers with intellectual disability (Hindmarsh, Llewellyn & Emerson, 2017)

The number of parents with intellectual disabilities who are parents is on the rise. For example, in a recent study of adults with intellectual disabilities in the United Kingdom, one in 15 interviewed were parents. It is therefore im-

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portant to examine the quality of life available to parents with intellectual disabilities and their children, and the support systems that enhance this lifestyle (Tarleton & Ward 2007). Children with intellectually disabled parents may also have developmental risks. In a large representative population-based sample research showed that parental intellectual disability was associated with increased risk of child developmental delay, child speech and language problems, child behaviour problems and frequent child accidents and injuries. Parental intellectual disability was also associated with increased risk of exposure to a wide range of environmental adversities (Emerson & Brigham, 2014)

Upon reviewing other studies it is observed that some work has been done concerning parents with intellectual disabilities. This study's involved the needs of children with special education who have parents with intellectual disabilities. The problem of this study is the lack of comprehensive intervention planning for children with special education needs who have parents with intellectual disabilities. The absence of intervention and monitoring system added with lack of awareness activities for such families is another important research area to be explored.

In the context of social work, one of the fields of disability work is the advocacy for disabled individuals who face social discrimination, stigmatization, or other relevant issues (Lysaght, et al.,2017). Social workers working with disabled individuals and their families need to work on the societal adaptation of parents with intellectual disabilities and activate necessary support mechanisms for their children (Xun, Jiao & Deng, 2024). This study aims to serve as a useful resource for social workers working in the field in managing such cases.

The obejctive of this study is to understand the experiences of employees working in official private education institutions regarding children of parents with intellectual disabilities and contribute to the scientific field. The research question of this study are: 1) What are the selfcare problems of children with special education needs who have parents with intellectual disabilities? 2) What are the needs concerning psychosocial support for children with special education needs who have parents with intellectual disabilities? 3) What skills can be provided to ensure the social participation of parents with intellectual disabilities and support their children with special education needs?4)What should be the psychosocial and educational framework model for parents with intellectual disabilities and their children with special education needs?5)What social work applications can be developed for parents with intellectual disabilities and their children with special education needs?6) How should law and regulation studies be? 7) What are the perspectives on ethical evaluation?

## **METHOD**

A qualitative method was used in this research. The study adopted a phenomenological design, highlighting the exploratory nature of qualitative research. Six focus groups were formed for the study. These groups were classified to two: i) psychosocial support professionals (PSP) which includes focus groups such social workers, psychologists, and psychological counselors. and ii) special education professionals (SEP) the focus groups included special education teachers and other educators working in the special education field. Data were obtained from two PSP groups, two SEP groups, and two mixed groups of PSP and SEP. All group members consist of different participants. Focus groups were chosen due to the rich data they provide through group dynamics, exchanges of ideas, and brainstorming that bring innovative ideas.

The study was conducted in Kütahya, a city in Türkiye's Aegean Region with a population of 575,000. The starting point of the study was the experiences obtained during a collaboration at Kütahya Special Education Kindergarten. From observation, noted that there are increase in the number of children with special needs who have parents with intellectual disabilities and expressed the need for research and development activities on this matter, it was decided to conduct this study. Due to confidentiality of personal information, the exact number of families in the province could not be reached.

Focus group members consisted of multidisciplinary professionals actively working or recently assigned elsewhere but experienced in the research scope at Kütahya Special Education Kindergarten. Participants were included in the study based on the purposive sampling characteristics provided below.

First, a total of 102 professional staff members (social workers, psychological counselors, special education teachers, preschool education teachers) working or previously worked at Kütahya Special Education Kindergarten were invited to participate via email. To identify professionals with experience working with special education children of parents with intellectual disabilities, an invitation question was asked:"What is your experience working with

special education children of parents with intellectual disabilities?"Responses were rated as "no experience," "some experience," and "sufficient experience." The invitation also included gender, age, marital status, years in the profession, and working duration at the special education kindergarten to prepare effective and efficient focus groups. The purpose of this preliminary assessment is to prepare the groundwork for forming effective and productive focus groups, consisting of those who have the best experience with the situation at the center of the research, have specific experience in this field, and have worked at the mentioned preschool for a certain period.

Second, based on the preliminary assessments, PSP (Psychosocial Support Professionals) and SEP (Special Education Professionals) groups were formed. In Kütahya, there are special education kindergarten students who have parents with intellectual disabilities. Preliminary assessments focused on including professional staff with high communication frequency with these families and significant professional experience. PSP groups have engaged in discussions on social integration, basic needs, and ethical issues. SEP focused on topics such as self-care, behavior, and cognitive development. Eighteen professionals directly working with the target applicant system were invited to the focus groups. Similarly, the same number of professionals were invited for the SEP groups. Participants selected for the mixed group were those with more seniority and experience in the field.

Inclusion Criteria for PSP Groups are such: i)having practical experience in this field, experience working with parents with intellectual disabilities, ii)graduated from one of the psychosocial field professions, iii)worked in the Psychosocial Support teams of Kütahya Special Education Kindergarten, iv)identifying the social problems mentioned by SEP, v) the voluntary consent. Nineteen PSP practitioners expressed their interest in participating in the research.

Inclusion Criteria for SEP Groups includes: i) communication with the relevant children within the scope of special education in this field, ii) bachelor's degree in special education, iii) experience in the field, and iv) the voluntary consent.

Eighteen PSP professionals and eighteen SEP professionals fully participated. Some participants could not join due to the time constriction of the focus group sessions and personal health issues. Researchers communicated with all participants, reviewed the inclusion criteria, provided information about the topic, summarized the

research objectives, obtained informed consent, and coordinated the focus group participation. Participants' informed consent was obtained, and the planning for focus group participation was coordinated. The characteristics of the participants are provided in Table 1.

This study received ethical approval from the Ethics Committee of Kütahya Health Sciences University on 10, July, 2023, reference number 2023/08-25. The research was conducted using a three-phase exploratory sequential design.

Two PSP groups were formed, each consisting of six members. Discussions within these groups focused on professional distribution and years of experience.

The data from PSP groups were presented to two SEP focus groups, each with six members, for further evaluation.

Mixed focus groups, each with six PSP and six SEP professionals, addressed remaining issues and aimed for consensus on the results. The focus was on completing and finalizing the missing aspects from previous focus groups and achieving consensus on the obtained results.

A total of six focus group sessions were conducted, with 36 participants in total. The sessions took place from October to December 2023 via video conference, with each session lasting two hours. The focus groups were managed by the researchers. The researchers have experience in conducting focus group discussions and workshops. They hold a master's degree in applied family counseling and possess theoretical and practical knowledge in group psychotherapy. They are experts in therapeutic communication and are active academicians in the field of social work, continuing their academic careers and conducting research. During the research, student assistants were asked to help with the transcription of all discussions. Participants were reminded of the confidentiality principle and informed that the sessions would be recorded. Consent was obtained from all participants regarding this matter. In the focus groups, the researchers served alternately as group leaders and assistant group leaders. The group leaders followed a semi-structured interview form. The discussion topics are provided in Table 2.

During the analysis phase, the researchers reviewed all the content transcribed from the discussions. This process involved organizing all focus group discussions and anonymizing the speakers. In the coding process, the researchers cross-coded and measured the consistency of the codes among themselves. According to Miles and Huberman's validity and reliability coefficient

Table 1. Characteristics of participants

Characteristics of participants(N=36)

participants(N=36)			
		Psychosocial Support Professionals	Special Education Professionals
Total		n=18	n=18
Sex	Female	8	7
	Male	10	11
Age in Years	26-30	10	8
	31-35	3	5
	36-40	3	4
	40+	2	1
Total professional experience in years	< 5	2	3
	5 - 10	10	11
	10 - 15	5	2
	15+	1	2
Specialist title	Child Development and Education specialists,	5	
	Psychological Counsel- ors,	7	
	Social Workers,	6	
	Preschool Teachers,		8
	Special Education Teachers.		10

calculation, the code consistency among the coders was calculated as 82.5%. There are two coders. One of them is first author and one of them is independent academic coder. The coding of the study was done using the MAXQDA 2022 program. Content analyses were conducted on the data obtained from the focus groups to answer the research questions. The researchers observed that the codes were concentrated on deficiencies and needs. Additionally, it was noted that ethical issues were frequently discussed. The themes, categories, and sub-categories related to the codes are provided in Table 3.

## **RESULT AND DISCUSION**

Three main categories were identified from the analysis of the data obtained from the study: Support Needs, Area of Lacking, Ethical Issues.

# **Support Needs**

The primary focus of professionals in focus groups often revolves around the inadequacies of parents with intellectual disabilities. In this regard, it is understood that issues related to

psychosocial support needs, social support needs, educational needs, requirements concerning legislation, and cognitive support needs have been raised in focus groups.

# Psychosocial Support Needs

Psychosocial support needs were identified as one of the most crucial issues for parents with intellectual disabilities. The focus groups frequently emphasized the necessity for families to receive psychosocial support, as well as the need for specialized support for the children.

"It is difficult to cope with certain situations within the school. When the family cannot provide the necessary support to the child, progress becomes very challenging. Considering these situations, I believe that psychosocial support is extremely essential." (SEP, FG-2)

"In the case of identifying a parent with intellectual disabilities, the child should receive psychosocial support." (PSP, FG-1)

It was stressed that interventions should be made at the right place and time through case follow-up for families and children. It was seen that the developmental periods of children should be

## Table 2. Semi-structured Moderating Guideline

## **PSP Focus Groups**

What is the most discussed topic in this field from a psychosocial perspective?

What situations do you most often discuss with parents with intellectual disabilities or their relatives?

What are the psychosocial support needs of children who have parents with intellectual disabilities?

How should social participation be?

What should be the model of practice for supporting parents and children?

What should be the macro applications, ethical values, and legal regulations for psychosocial support?

## **SEP Focus Groups**

How do you evaluate the outputs of the psychosocial focus groups?

How do you assess learning, behavior, and psychosocial development processes?

How can special education be coordinated with psychosocial support?

What kind of model can be proposed for coordination?

What are your views on practices and policies related to psychosocial support and special education?

## **Mixed Focus Groups**

Is there any different idea from the previous focus groups' outputs?

Based on your experiences, how do you evaluate the thoughts that emerged in the focus groups? What should professional practices and policies be?

provided in the best way and their rights should be observed in line with children's rights. It is understood that various support programs should be developed in order to observe the best interests of children.

> "From an ethical perspective, since parents may be insufficient in protecting their rights, other family members often make important decisions for the children. For children who cannot defend their rights, support units and close follow-up are very important." (PSP, FG-2)

> "If possible, a caregiver other than the parent with intellectual disabilities should be provided for the child. If a caregiver cannot be provided, the state should take the child under its supervision and implement programs for regular follow-up and intervention when necessary." (SEP, OG-3)

It is also understood that families and children need professional support and, if possible, supervised child-rearing programs should be developed and implemented.

"Psychological support that is not provided or cannot be provided within the family at an early age should be given by a specialist." (SEP, OG-1)

"I advocate for supervised child-rearing for parents with intellectual disabilities, as uninten-

tional mistakes made during critical periods (especially preschool years) can be detrimental to children's lives." (SEP, OG-2)

## Social Adaptation Support Requirements

Another prominent issue in the focus groups was the need for social support mechanisms for parents. Social adaptation support emerged as an important aspect of social support needs. It was emphasized that creating social support networks within the school environment is crucial, as it significantly affects social adaptation. It was also mentioned that these parents should receive integration education similar to their children. Additionally, it has been emphasized by participants as a crucial social integration issue that institutions and organizations need to work in a coordinated manner regarding such cases.

"Ensuring that parents of peer groups meet and providing support such as letting them know they are not alone can be beneficial. We try to conduct these activities to the best of our abilities at the school level." (SEP, OG-3)

"Support and integration activities can be carried out with volunteer families for parents with intellectual disabilities, just like with students." (SEP, OG-2)

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Table 3. Themes, Categories, Codes

Theme	Cat- egory	Sub-category	Codes	Code Frequency
Experiences and Social Work Requirements for Children of Parents with Intellectual Disabilities  Suppon Needs  Ethica	Area of Lacking	Lacking Area of Self- Care	Insufficient Reinforcement of Self-care Deficiency Education, Personal Hygiene Deficiency, Bathing Habit Deficiency, Clothing Cleanliness Issues	143
		Lacking Area of Behavaiour Training	Social Adaptation Deficiency, Behavior Awareness Deficiency, Toilet Training Deficiency, Families' Learning Defi- ciency	141
		Lacking Area of Psychosocial Development	Deficiencies in Access to Basic Rights, Psychosocial Development Deficiencies within the Family	129
	Support Needs	Educational Needs	Parental Education Requirements, Parental Support Education Requirements, Basic Needs Education Requirements, Education Needs in Childcare	157
		Social Adaptation Support Requirements	Need for Coordination Between Institu- tions and Organizations, Social Adapta- tion Support, Family-based Social Sup- port Needs, Need for Support Personnel	163
		Cognitive Behavioral Support Requirements	Need for Support during Leisure Times, Support for Self-care Skills Competency, Support for Language and Speech Skills	139
		Psychosocial Support Needs	Supervised Child Rearing Support, Need for Professional Support, Case Follow- up Support, Psychosocial Support for the Child, Psychosocial Support for the Family	172
		Legislative Regulation Requirements	Monitoring of Parents' Eligibility to Have Children, Legislative Regulations for Parental Education, Legislative Efforts to Facilitate Access to Basic Rights, Screening of Parents' Genetic Background, Social Adaptation-based Legislative Efforts, Law Amendments to Prevent Abuse	146
	Ethical Issues	Ethical Dilemmas Regarding Birth Preven- tion, Access to Services and Counseling, Social Equality, Confidential- ity and Privacy		141

"All institutions should work together to facilitate their adaptation to life." (SEP, OG-3)

Another significant support mechanism for social adaptation is the support from the social environment. It was noted that support persons are important for the care and upbringing of children of parents with intellectual disabilities, and families should be supported in this regard. Statements about the involvement of extended family support in the adaptation process were also

included in the focus groups.

"The self-care of children with parents with intellectual disabilities varies according to the family's situation. In cases of severe disability, usually, a second family elder, typically the grandmother or grandfather, takes care of the children." (SEP, OG-1)

"The basis of our school program is to instill 'self-care skills' and 'social adaptation skills' in students, which directly affects whether parents

participate in social life or become isolated from society." (PSP, FG-1)

## Educational Needs

It is understood that parents with intellectual disabilities have educational needs in various areas, some of which require direct education and others in which they need to be part of the educational process for their children. The focus groups frequently discussed the necessity of providing education related to parenting responsibilities and being a parent. It was emphasized that these parents should not only receive education themselves but also be involved in the educational processes provided to their children.

"Macro applications can include providing education to children of parents with intellectual disabilities on basic life skills to enable them to continue their lives independently." (SEP, OG-3)

"Children of parents with intellectual disabilities come to school without showing the necessary psychosocial development within the family. In school, this situation becomes very difficult to progress when the family cannot provide the necessary support. Considering these situations, I believe that psychosocial support is very essential." (PSP, OG-2)

In the focus groups discussing the necessity of education related to child care, it was emphasized that awareness training should be conducted to understand and meet basic needs.

"Due to diagnoses like intellectual disability and autism, training can be given to other individuals who provide support for the child's care in terms of physiological needs, and social support can be given to the child to meet their need for belonging and love." (PSP, OG-1)

"To support children, first, the family should be educated in all areas of development to contribute to the child's development. After the family receives the necessary education, supporting the child will be easier." (SEP, OG-2)

# Legislative Regulation Requirements

One of the frequently discussed topics in the focus groups was the necessity of regulatory arrangements regarding this situation. It was stated that regulatory work is necessary in some areas based on the assumption that both the family and their children could experience lifelong victimization. It was evaluated that some aspects of the regulations should be discussed from an ethical perspective. Accordingly, it is understood that there should be controls over couples with intellectual disabilities having children, manda-

tory support through education for such parents, ease of access to fundamental rights and services, research on genetic screenings, and regulations to prevent the misuse of societal services and harmony.

"Laws should be enacted stating that disabled individuals should not have children, and this control should be maintained very well." (SEP, OG-2)

"Early detection practices related to the genetic transmission of intellectual disabilities should be implemented, and if deemed necessary, regulatory measures to mandatorily prevent gene transfer should be established through legal arrangements." (SEP, OG-1)

"Laws and regulations should be prepared comprehensively, covering all needs and groups without allowing misuse. These laws should include mechanisms that can be monitored and enforced with sanctions if necessary." (PSP, OG-3)

## Cognitive Behavioral Support Requirements

Another important requirement for parents with intellectual disabilities was assessed to be the development of support mechanisms aimed at enhancing cognitive behaviors. The importance of conducting activities to effectively and efficiently utilize the parents' free time was frequently emphasized by participants. It was suggested that it would be appropriate to identify and schedule parents' free time and support them in fulfilling other routine tasks within the scope of family responsibility.

"Pre-screening should be conducted to determine the type and areas of insufficiency of the intellectual disability for both the parents and the child. Support classes can be established for the free time outside of the child's education, and psychosocial work can be carried out for children and parents identified as insufficient." (PSP, OG-3)

"They can acquire skills to perform their daily routine tasks. In this way, they can be role models for their children and acquire the ability to perform daily tasks without assistance." (SEP, OG-2)

Professionals in the focus groups expressed opinions that it would be appropriate to provide support related to acquiring self-care skills and language and speech skills. In this context, it was noted that developing behavior skills that improve the quality of life for both the parents and the children would directly affect social harmony.

"Guidance should be provided to enable them to continue their lives independently, support development areas and academic skills, and offer rehabilitation for families and individuals in need." (SEP, OG-1)

"They can acquire self-care skills, social and community adaptation skills, receptive and expressive language skills, and fine and gross motor skills." (SEP-OG-2)

## Areas of lacking

Various deficiencies related to parents with intellectual disabilities were mentioned in the focus groups conducted within the research scope. Prominent deficiencies include self-care, behavior training, learning, and psychosocial development.

## Lacking Area of Self-Care

Focus group studies revealed that parents with intellectual disabilities have self-care deficiencies. Within the scope of self-care deficiencies, it was noted that children receiving special education face issues with clothing and personal hygiene, and the primary reason for this is the parents' inability to provide care. Participants emphasized significant issues such as neglect in self-care skills, such as bathing, and the presence of problems with clothing and personal hygiene among students coming to school.

"Due to their parents' disabilities, children often do not pay attention to their daily hygiene. There may be children who do not come to school with clean clothes, and their nail and body cleanliness may be insufficient or unmet." (SEP-OG-2)

"We communicate with the person responsible for the child's self-care and provide our suggestions. When there is no responsible family elder, children often do not come to school clean in terms of both body and clothing, and progress is difficult since the training provided is not implemented at home." (PSP, OG-1)

"There are deficiencies in self-care skills and sometimes issues with the cleanliness and maintenance of the clothes the child wears to school." (SEP, OG-1)

"Self-care skills are at a very low level. The reason for this is the lack of a model family in front of them. Even if families take care of their own self-care, it does not reflect on the child as they do not have the capacity to teach it." (PSP-OG-1)

The inadequacies of the training provided on self-care skills were also emphasized. It was discussed in the focus group that the training provided should be supported by skill acquisition at home.

"We encounter problems such as the inability to adequately support the self-care skills training provided at school at home." (SEP, OG-2)

"Social integration activities can be conducted on this issue, but the basic observation is that self-care skills are insufficient in such families." (PSP, OG-1)

"Especially self-care skills need to be supported. Because when their self-care is lacking, they are excluded by other children and their families." (PSP, OG-2)

## Lacking Area of Behavaiour Training

A frequently highlighted issue was the lack of awareness of parents with intellectual disabilities regarding their behavior. Participants frequently discussed the lack of various habits that should be displayed in daily life and the exclusion of children receiving special education because they do not acquire these behaviors.

"They can acquire skills to perform their daily routine tasks. In this way, they can be role models for their children and acquire the ability to perform daily tasks without assistance." (SEP, OG-2)

"When parents cannot be role models and cannot provide input to the student, it becomes difficult for our students to show social and cognitive development." (PSP, OG-1)

"Since the children are generally preschool-aged, they cannot fully meet their self-care needs. When there is a intellectual disability in the family, children who do not encounter any role models at home acquire these skills later, only after starting school." (SEP, OG-2)

It was also noted that another significant deficiency in behavior training is related to social adaptation. It was stated that parents and children are not fully effective in social adaptation training and that more advanced practices are needed for such training.

"Children of parents with intellectual disabilities may have intelligence functions below a certain average and may experience adaptive behavior problems." (PSP, OG-2)

"Children may be insufficient in social skills such as interpersonal relationships and solving social problems. A child who cannot perform daily life activities may experience losses in practical skills. (SEP, OG-4)"

# Lacking Area of Psychosocial Development

It was understood that parents with intellectual disabilities face issues in accessing basic needs and in psychosocial development within the family. Participants indicated that students have special needs in accessing health and other basic services, and parents either lack sufficient awareness or face limitations in accessing these

services. It was also noted that there are issues in developing family communication and behavior patterns.

"When students get sick, they are sent to school without being taken to the hospital. Parents have difficulty showing their love. This can lead to behavioral disorders such as irritability in children." (PSP, OG-1)

"Children of parents with intellectual disabilities come to school without showing the necessary psychosocial development within the family. In this situation, psychosocial development cannot be fully realized, and they cannot adapt to school." (SEP-OG-1)

#### **Ethical Dilemmas**

Participants drew attention to some ethical dilemmas within the scope of the research. It was noted that there are ethical dilemmas regarding ensuring social equality, access to services and counseling, control of childbirth, and issues of confidentiality and privacy, and that policies should be developed within the framework of ethical values regarding these issues.

"Having children is, of course, everyone's right, but having an uninformed and unmanageable child is more dangerous. Measures should be taken to consider the consequences of this." (SEP, OG-1)

"I am aware that legal regulations regarding the parenthood of individuals with intellectual disabilities are against the principle of equality. However, I believe that such regulations would serve as a preventive measure, as this situation could negatively impact the psychological, cognitive, social, linguistic, and physical development of the individuals who will be born." (PSP, OG-2)

"Maximum care should be taken regarding confidentiality and privacy in all types of education and support services provided. It is necessary to take all kinds of precautions to preserve the principle of social equality, access to services, and counseling." (SEP, OG-1)

Based on the results obtained from the research, it was found that there are "areas of lacking" and "needs" related to parents with intellectual disabilities and their special needs children. Areas of lacking include lacking area of self-care, lacking area of behavaiour training, and lacking area of psychosocial development. Regarding needs, data were obtained on educational needs, social support needs, cognitive support needs, psychosocial support needs, and the need for legislative changes. Additionally, important codes related to ethical elements emerged in

the focus groups, highlighting ethical dilemmas related to preventing birth, access to services and counseling, societal equality, privacy, and confidentiality.

## Discussion

The research showed that parents with intellectual disabilities have significant needs in term of support, lacking areas and dilemmas. Among these, psychosocial support needs were identified as the most important. Psychosocial support needs of parents with intellectual disabilities, who face issues such as stigmatization or exclusion by society, were found to be prominent (Wade, Llewellyn, & Matthews, 2008). A systematic review found the psychosocial supports could be non-pharmacological and non-physical interventions adult intellectual disabilities Thalen, Volkers & van Oorsouw & Embregts, 2022).

Adaptation was identified as another significant need for parents with intellectual disabilities, who are likely to be affected by social problems such as societal stigmatization. Ensuring the healthy and safe adaptation of parents to social life during the adaptation process is considered an important requirement (Glazemakers & Deboutte, 2013) "The necessity for intellectually disabled parents to receive education in order to fulfill their general family responsibilities has been emphasized throughout the research period. Particularly, the importance of conducting education specifically for intellectually disabled parents has been highlighted. Furthermore, it is emphasized that these specialized educations, seen as an important social support element, should be evidence-based and include interventions (Coren, Ramsbotham & Gschwandtner, 2018). It is emphasized that it is important to implement developments suitable for the dynamics and services of society regarding the requirements of laws and policies, focusing on respect, choice, social relationship building, and assuming the role of parenting (Llewellyn, 2013).

A significant issue highlighted within the scope of inadequacies addressed during the focus group process is self-care inadequacy. It can be said that there are many self-care issues in the field of disability. Therefore, it is noted that self-care holds a central position in health development, and it is stated that enlightening educations have an important place in interventions in this field (Cross, 2007). In another study, it is stated that children of intellectually disabled parents are taken under protection system due to their inability to provide necessary self-care (Llewellyn & Hindmarsh, 2015). As stated in the requirements

section of the study, it is evaluated that the importance of intellectually disabled parents receiving education in fulfilling their family responsibilities is great. However, in some cases, the inadequacy of parents in receiving education can make this situation difficult. At this point, emphasis is placed on the importance of primary family support (Collings & Llewellyn, 2012).

It can be observed that professionals working with intellectually disabled parents generally face many ethical dilemmas (MacIntyre, Stewart, & McGregor, 2019). In a study conducted, it was evaluated that the source of ethical dilemmas stems from the balance sought between parenting rights and meeting children's needs (Joreskog & Starke, 2013). While interventions focusing on the best interest of the child are made in practices related to intellectually disabled parents, it can also be seen that dilemmas arise with some legislation and policies (Feudtner & Brosco, 2011).

## **CONCLUSION**

In this research, a comprehensive perspective was adopted on the conditions of special education needs children with intellectually disabled parents, and attempts were made to define the phenomenon within focus groups consisting of professional groups working in special education institutions. Consequently, it is evaluated that intellectually disabled parents and children with special education needs have various needs in various subjects, and difficulties may be encountered in establishing a sustainable family life cycle due to some inadequacies.

It can be observed that it is important for the unmet needs of intellectually disabled parents and children with special education needs to be met by societal dynamics or governmental procedures in order for them to lead a quality life. In this context, it is evaluated that the role of case follow-up, an important role of the social work profession, stands out more prominently here. Case follow-up becomes important in terms of supporting such special families.

In addition to the self-care inadequacies of children, their inability to sustain their special education effectively and efficiently, and the lack of necessary family support in the special education process, lead to even greater problems. It has been observed that professionals working in institutions face limitations in mechanisms they can activate in this regard and are confronted with ethical dilemmas. Although cognitive behaviors pose a requirement for education, the limited education of parents and children can also lead to problems in sustainable family life.

According to the findings of the study, it is recommended that counseling services be provided specifically to intellectually disabled parents, focusing particularly on the social work profession. It is also recommended that competent authorities conduct case follow-ups of such families closely monitoring the situations of parents and children. Furthermore, it is of great importance to guide these families and children towards the social support mechanisms they need. Advocacy for necessary legislative and policy changes is required to effectively address ethical dilemmas that professionals may encounter and to ensure sustainable services.

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