Ugur Onur Gunden [1]
ORCID: 0000-0001-7733-391X

Veysel Aksoy [2]
ORCID: 0000-0003-1020-8326

Severity of Disability and Parental Perception: A Qualitative Investigation*

Abstract

In this study, the perceptions of parents of children with developmental disabilities regarding the severity of disability were tried to be revealed. The studies, which are conducted in order to reveal the perceptions of parents of children with disabilities regarding the severity of disability, generally focus on the main points such as problem behaviors, social adaptation, and language and communication skills. In this research, semi-structured interviews were performed with 8 parents in order to reveal the perceptions regarding the severity of disability. The semi-structured interviews were analyzed through content analysis method. As a result of the analysis, occurring themes regarding the severity of disability perceived by the parents of children with developmental disabilities consist of learning and success, social interaction and adaptation, language and communication, problem behavior, physical difficulties and daily living skills. The obtained findings were discussed in line with the related literature.

Keywords: developmental disability, perception, perceived severity of disability, parents

Introduction

Disability is defined as a situation resulted in a total or partial loss in the functions of the individuals caused by an injury (Heward et al., 2017). Developmental disability, on the other hand, expresses the skills and features in which differences from norm groups are observed. Cognitive, communicative, social, and motor skills differences occur before the age of 22 (Odom et al., 2007). Under the umbrella term of developmental disability, there are disability groups such as Autism Spectrum Disorder (ASD) and Down Syndrome as a part of the Intellectual Disability (Heward et al., 2017). ASD is defined as a neurodevelopmental disorder characterized by social

communication and interaction, and repetitive behaviors in the Diagnostic and Statistical Manual of Mental Disorders (DSM-5) (APA, 2013). Down syndrome, on the other hand, is evaluated as a disability with genetic background (APA, 2013), and this disability is caused by an error in chromosome division (Selikowitz, 2008; Kuder, 2018).

Severity of disability

Individuals with disabilities have to be identified and even classified in order to access the services for their needs easier (Heward et al. 2017). Since the classification is a phenomenon related to the severity of disability in terms of restricting the functions of the individual, the severity of disability concept stands out at this point.

[1] M.Ed., Anadolu University, Research Institute for Individuals with Disabilities, Eskisehir, TURKEY.
e-mail: uogunden@anadolu.edu.tr
*Corresponding author
[2] Ph.D., Anadolu University, Research Institute for Individuals with Disabilities, Eskisehir, TURKEY.
e-mail: vaksoy@anadolu.edu.tr

This concept, which can be defined as the impact of the disability on the capacities of the individuals (Guscia et al., 2006), is classified from various aspects. The severity of ASD was categorized within the definition as; Level 1 (Requiring support), Level 2 (Requiring substantial support), and Level 3 (Requiring very substantial support) (APA, 2013). The classification was made over intellectual functions, functional linguistic performance, and a combination of these within the International Statistical Classification of Diseases and Related Health Problems (ICD-11) (WHO, 2018). While intellectual disability was classified as mild, moderate, severe, and profound in DSM 5, there are also categories of children under the age of 4 (provisional) and unspecified category in which intellectual functions and adaptive skills cannot be evaluated in ICD-11 in addition to these categories (WHO, 2018). The Intelligence Quotient (IQ) tests are seen as an essential classification within the traditional classification of intellectual disability and Down Syndrome, accordingly. According to this classification, the severity of disability is classified as mild, moderate, severe, and profound (Heward et al., 2017).

Severity of disability and main restriction areas

In parallel with the severity of disability, certain restrictions are observed in individuals with developmental disabilities. These are gathered under the titles of intellectual properties, sensorial properties, communication skills, emotional and behavioral development, and physical properties (Kirk, Gallagher, and Coleman, 2009). Main restriction areas specific to the disability in individuals with ASD appear as social interaction difficulties, communication problems and repetitive behaviors, or intense restricted interests (Centers for Disease Control and Prevention [CDC], 2016). It is expressed that individuals with Down Syndrome display restrictions that are generally based on physical, neural, cognitive, behavioral, and emotional aspects (Morales and Lopez, 2013). It is also stated that individuals with Down Syndrome have specific physical traits typically such as resembling each other, small head and short neck, upward slanting eyes, small mouth, large tongue, dental anomalies, small ears, low muscle tone, wide hands, short and chubby fingers, a single short crease across the palm of the hand, and chunky length (Diken et al., 2016).

Families of individuals with disabilities

Although there are various types of family, which is defined as the smallest social group in terms of social continuity, (Murdock, 1965), within the society, it is expressed that the most common type is nuclear family, which consists of parents and children (Berns, 2010). Families have various functions such as sexuality, economy, reproduction, education, daily care, sociality, and health in terms of sustainability between both child and parents (Hallahan, Kauffman, and Pullen, 2014). The inclusion of a child with a disability into the family may impede these functions. It is stated that parents show psychological reactions such as shock, denial, accusation, anger, sadness, and rage to a large extent to this situation that has a severe impact on the parents (Hallahan, Kauffman, and Pullen, 2014). It is stated that the nature of these reactions displayed by the parents may be related to their ways of perceiving their children and the disability-related traits of their children and that even the sociocultural specific variables (Dovgan et al., 2019) and characteristics of the parents are effective on this perception (Hock and Ahmedani, 2012). Hence, it is reasonable for parents' subjective experiences and ways of perceiving the given situation to cause various reactions. At this point, the fact that the parents' reactions to disability are directly related to the severity of disability, which they perceive, renders the concept significant.

Severity of disability and perceptions of the parents

Although the severity of disability is tried to be locked inside a category and quantitative numbers, the personal perceptions of the parents significantly determine the reactions they display. It can be said that positive and negative perceptions regarding individuals with developmental disabilities display direct proportion in terms of psychological variables (Griffith et al., 2010; Lickenbrock, Ekas, and Whitman, 2011). In other words, the negative perceptions regarding the types of

developmental disabilities may psychologically cause parents to display negative reactions, and positive perceptions may cause them to display positive reactions. In this regard, in the studies conducted with the parents of individuals with developmental disabilities, children were classified by their parents regarding various variables. The areas which were stated as more serious by parents in relation with the severity of disability were expressed as the characteristic of the child (Webster Stratton and Hammond, 1988; Kasari and Sigman, 1997; Colavita, Luthra and Perry, 2014; Dovgan et al., 2019), adaptive behaviors (Bishop et al., 2007; Colavita, Luthra and Perry, 2014), restricted and repetitive behaviors (Bishop et al., 2007), problem behaviors (Webster Stratton and Hammond, 1988; Konstantareas and Homatidis, 1989; Baker et al., 2003, Hastings et al., 2005; Griffith et al., 2010; Colavita, Luthra and Perry, 2014), social skills (Griffith et al., 2010; McStay et al., 2014), language and communication skills (Konstantareas and Homatidis, 1989; McStay et al., 2014; Colavita, Luthra and Perry, 2014), and cognitive skills (Konstantareas and Homatidis, 1989). As stated, the main areas in which individuals with disabilities display restrictions are gathered under the titles of social skills, language and communicative skills, cognitive skills, problem behaviors, adaptive skills, and temperament of the child. Accordingly, it is stated that conducting research on how parents of children with disabilities perceive the situation of their children will be beneficial (Akkok et al., 1992) and there is a need for researches revealing the experiences regarding the variables related to the disabilities (Gulec Aslan, Cihan and Altın, 2014). Similarly, it is also emphasized that there are limited studies analyzing the severity of disability in individuals and the perceptions of parents, and the severity of disability in parents of children with disabilities are not focused on despite the fact that they display a more negative psychological picture than the parents of individuals making a normal progress in the psychological sense (Kissel and Nelson, 2016). Therefore, in this phenomenological study, it was aimed to observe the ways of perceiving the severity of disability of parents of children with disabilities and the situations related to the severity of disability from the eyes of the parents. Accordingly, answers to the following research questions were sought:

1. How do parents see the effects of severity of disability on their children?

2. How do parents interpret the main limitation areas of their children regarding the severity of disability?

Method

Research design

This research was designed with the phenomenological design, which is one of the qualitative research designs since it was aimed to thoroughly reveal the experiences of the participants regarding a phenomenon. Phenomenology is preparing a ground to thoroughly reveal situations such as perception, experience, and knowledge regarding the situations faced in various ways (Yıldırım and Simsek, 2016). The experiences and knowledge related to these experiences of people are focused on through phenomenology (Patton, 2014). For these reasons, it was tried to be examined how a phenomenon, which was experienced and continue to be experienced by parents regarding the disability and the severity of disability, corresponds to their perception in this study. It was considered that this perception is related to a dynamic process and may display changes in time.

Participants

In this study, 9 participants, one of them being the parent with whom the pilot interview was conducted, were included. When selecting the participants, criterion sampling (Merriam, 2009) and volunteer sampling (Remler and Ryzin, 2011), which were determined as directly related to the aim, among the purposive sampling methods were used. It is stated that 6 to 10 participants are enough for a study based on the semi-structured interview (Smith, Flowers, and Larkin, 2009). In addition, it is expressed that it is important for data sources to have experiences regarding the phenomenon in phenomenological studies (Yıldırım and Simsek, 2016). The acceptance criterion was determined as having a child with disability and being a volunteer for participants to participate in the study. The descriptive information about the participants is presented in Table 1.

Table 1.

Demographic information of participants

Name	Gender	Age	Occupation	Age of the child	Gender of the child	Diagnosis
Esra	Female	42	Housewife	5	Girl	DS
Ela	Female	39	Housewife	5	Girl	DS
Fatma	Female	37	Teacher	6	Boy	DS
Ayşe	Female	43	Teacher	5	Boy	DS
Isa	Male	50	Retired soldier	3	Boy	DS
Osman	Male	35	Driver	4	Boy	ASD
Hatice	Female	41	Nurse	4	Boy	ASD
Hakan	Male	48	Inspector	5	Boy	ASD

Note: DS = Down Syndrome, ASD = Autism Spectrum Disorder

Five of the participants of the study are female and three of them are male. The average age of the participants is 41.8 and the average age of the children is 4.5. While five of the children are diagnosed with DS, three of them are diagnosed with ASD.

Data Collection Tools

Personal information form

A form was prepared in order to collect demographic information regarding the participants and their children with disabilities. In the form, information on their names, ages, occupations, educational backgrounds, and age, gender, and diagnosis of their children were included.

Semi-structured interviews

It was expressed that the main data collection technique in phenomenology is interviewing (Yıldırım and Simsek, 2016). The interviews are used in order to reveal the perceptions, descriptions, and meanings of persons regarding the reality and their own reality (Punch, 2013). In this study, the semi-structured interview technique, which provides convenience to the researcher from many aspects, was used. It is stated that semi-structured interviews are frequently used in pedagogy researches due to their flexibility and a certain level of standard (Turnuklu, 2000). The opinions of three academicians, who are experienced and experts in their fields, were received while preparing the interview questions. Accordingly, a pilot interview with a parent and semi-structured face-to-face interviews with eight parents were performed through the questions prepared based on the related literature towards the target group. Performed in line with the semi-structured interview form, which consists of 13 questions in total, lasted for 25 minutes on average.

Process and Data Collection

At the first stage, the topic was selected and then the research questions were prepared. Then the research process was designed. The interview questions were prepared during this process. The pilot application (Yıldırım and Simsek, 2016) was performed in order to evaluate the interview. First, the participants having the appropriate sampling were determined and verbal permits were taken in order to present the phenomenon regarding the severity of disability, which forms the focus of the research. The interviews were performed in an environment in which participants would feel comfortable in terms of sound, light, and temperature. The permits of the participants were taken through the consent form, voice recordings were performed after informing the participants written and verbally in terms of ethical rules, analyses were conducted, and the report of the study was written. When planning the research process, the process scheme for qualitative research, which was suggested by Johnson and Christensen (2016), was used. The scheme used as a guide during this research is presented in Figure 1.

Figure 1.

*Research process*

Data Analysis and Compatibility

Analyses were performed through content analysis by itemizing the voice recordings. It is stated that the main objective in content analysis is to reach the concepts and relations through which the data can be explained. In this way, the relations between concepts and themes are realized (Yıldırım and Simsek, 2016). While analyzing the data, it was acted through the stages suggested by Yıldırım and Simsek, (2016) as a) coding the data, b) finding themes, c) organizing the codes and themes, and d) defining and interpreting the data. In addition, the experiences regarding the phenomenon were conveyed through quotations while presenting the data (Yıldırım and Simsek, 2016).

The first application performed in terms of validation is content validity. Opinions were received from experts in their fields for the purpose of content validity (Buyukozturk et al., 2013). The correspondence percentage was calculated for the theme, code, and interview itemization in order to evaluate the compatibility of the data and findings, accordingly, (Buyukozturk et al., 2013), and the correspondence was

reviewed over the codes (Bogdan and Biklen, 2007). Finally, the voice recordings taken during the interviews were listened to by another researcher, and the reliability percentage was calculated. Over a 90% correspondence was reached in these analyses.

Results

As a result of the analyses, a total of 6 themes occurred as problem behaviors, physical difficulties, learning and success, language and communication, daily living skills, social interaction, and social adaptation. The themes are presented in Figure 2. Themes, categories, frequencies, and quotations regarding the themes are explained under the following titles. The codes are held at the main basis while conveying the findings. The combination of codes, sub-themes, and the combination of sub-themes created the themes. At the combination of themes, perceptions regarding the severity of disability occurred.
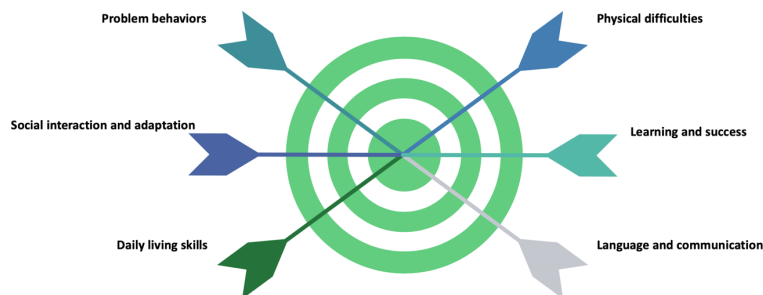
Figure 2.

Themes about the perceived severity of disability

Problem Behaviors

The first theme occurring at the end of the analyses was problem behaviors. Parents associated the problem behaviors, which they observe during the day, with the severity of disability under this theme. The problem behavior theme and its sub-themes are presented in Table 2. When Table 2 is reviewed, it is seen that the codes of stubbornness, acting uncontrollably, and hitting others are in the top three. In general terms, there are three sub-themes within this theme: personality traits, lack of self-control, and damaging/disruptive behaviors.

One of the participants, Hakan, expresses his personal experience regarding the eating processes as: *"He has to eat but he does not; he throws himself from the chair…".* Another participant, Ela, expresses the situation she experiences in social environments: *"She does not listen to me at all. She completely breaks the rules…".* Ayse also expresses the situation she experiences in social environments: *"He puts his hand inside his mouth and makes "GEV-GEV-GEV" sounds.".*

Physical Difficulties

The second finding creates a theme as physical differences. Parents associated the physical difficulties or motor restrictions, which they observe in their children, with the severity of disability under this theme. The physical difficulties theme and its sub-themes are presented in Table 3. When Table 3 is reviewed, it is seen that walking difficulties, eye hand coordination, and glances are in the top three. In general terms, there are physical difficulties including gross motor and fine motor within this theme.

Mr. Osman from the participants expresses the fine motor restrictions that he observes in his child as: *"He cannot hold a pen, for example; one of his difficulties is the inability to hold a pen…".* Mrs. Ela emphasizes the fact that the physical restrictions occur more when there are peers at present as: "*You feel the disability in the physical sense when there are peers at present.".* Another participant, Mrs. Hatice expresses that she observed retardation in the developmental sense in her child regarding the gross motor skills as: *"Our gait ignition happened late; everything really happens later.".* Moreover, the participant Hatice expressed her experience regarding the social aspect when they walk in the streets as: *"…the disability of my child is understood from his face; they look at our face like saying "you are disabled…".*

Table 2.

Problem behavior theme, categories, and frequencies

Sub-theme	Code	*f*	%
Personality traits	Stubbornness	6	75
	Disobedience	3	37,5
	Restricted behaviors	3	37,5
	Adult dependency	2	25
Lack of self-control	Acting uncontollably	6	75
	Crying	3	37,5
	Getting angry	3	37,5
	Eye contact	2	25
	Running	1	12,5
	Getting bored with activities	1	12,5
	Making inappropriate sounds	1	12,5
Damaging/Disruptive behaviors	Hitting others	4	50
	Throwing himself/herself to ground	4	50
	Damaging the objects	3	37,5
Total		41	

Table 3.

Physical difficulties theme, categories, and frequencies

Sub-theme	Code	*f*	%
Gross Motor	Walking difficulties	4	50
	Other gross motor skills	2	25
Fine Motor	Eye hand coordination	3	37,5
Physical appearance	Glances	2	25
	Difficulties in peer existence	1	12,5
Total		12	

Learning and Success

The learning and success theme occurred as one of the themes in which the maximum number of categories is included. Five of the participants associated the low learning speed, again, five of them associated the fact that learning is hard for their children, and four of them associated falling behind in development compared to the peers with the severity of disability under this theme. Learning and success theme, categories, and frequencies are presented in Table 4.

The participant Mrs. Esra expresses the frequent repetition need of her child during her learning experiences as: *"I help her, but when I said, "you can do the rest by yourself", she does not. She does not learn at first but learns at 10th-20th time.".* Mrs. Ela made a comment about the fact that learning is hard, which is another situation related to the learning, as: *"She cannot learn easily; I experienced this in toilet training in the most extreme way.".* Mrs. Ayse talks about the motivation, which is a necessary state for learning and success, as: *"…his motivation is low; it does not have consistency.".*

Language and Communication

Language and communication skills, which is a significant distinctive factor during the diagnosis process, occurred as another theme. Reflections of the severity of disability related to receptive and expressive language skills are especially seen within this theme. It is seen that parents listed the main restrictions in language and communication skills related to the perceived severity of disability as; restrictions in speaking, inability to express his/her needs, and using signs in communication. Communication and language theme, categories, and frequencies are presented in Table 5.

The participant Mrs. Esra expresses her perception of the severity of disability regarding the receptive language skills of her child as: *"You say 3 times, 4 times, 10 times, 20 times but she never understands…".* Mr. Hakan states that he sees the reflections of the severity of disability in the expressive language skills by emphasizing the functional language use as: *"He is a child who is able to tell the names of 500 pictures. The number of sentences he forms or words he uses in daily life is extremely low compared to 500…".* Mr. Osman emphasizes that his child cannot even fulfill a basic request made to him as: *"For example; he brings a glass of water from the kitchen or he does not even do the thing he is interested in most.".*

Daily living skills

Daily living skills occurred as another theme. It is seen that majority of the parents have common statements under this theme. The main categories and codes are toileting skills, eating skills, and independent dressing skills. While all parents associated the toileting skills with the severity of disability, six of them emphasized the eating skills and five of them emphasized the proper dressing skills. The categories and frequencies regarding daily living skills are presented in Table 6.

The participant Mr. Osman emphasizes the proper eating skills he observes between the settings as: *"For example; he is eating very well here. We cannot do this at home…".* Mrs. Ayse states that her child tries to display some skills and acts independently as: *"For example, he is able to wash his hands, but I do not let him. He tries to hold water with his hands, I mean, he tries to do whatever he wants.".* Mr. Isa mentions the restrictions and helplessness they feel as a result of the severity of disability as: *"He cannot fulfill his need to use the toilet; we have not been able to success anything (he refers to progress) about toileting.".*

Table 4.

Learning and success theme, categories, and frequencies

Sub-theme	Codes	f	%
Learning	Low learning speed	5	62,5
	The fact that learning is hard	5	62,5
	Believing in the inability to success	4	50
	The effectiveness of visual learning	4	50
	Inability to learn abstract situations	2	25
	Importance of intense education	2	25
	Learning with frequent repetition	1	12,5
	Monotonic learning	1	12,5
Faith in success	Falling behind in development compared to the peers	4	50
	Noticing the difference in development with peer existence	3	37,5
	Difficulties in problem-solving	2	25
	Low motivation	1	12,5
Total		34	

Table 5.

Language and communication theme, categories, and frequencies

Sub-theme	Codes	f	%
Receptive Language	Low learning speed	5	62,5
	Inability to understand what is said	2	25
	Receptive language falling behind the peers	2	25
Expressive Language	Restrictions in speaking	5	62,5
	Inability to express his/her needs	4	50
	Low-comprehensible expressive language	4	50
	Inability to express his/her living	3	37,5
Communication Choice	Using signs in communication	4	50
	Communication avoidance	4	50
	Clue-dependent speaking	1	12,5
	Diversifying the speech	1	12,5
Total		34	

Table 6.

Daily living skills theme, categories, and frequencies

Sub-theme	Codes	f	%
Self-care	Toileting skills	8	100
	Eating	6	75
	Dressing	5	62,5
	Bathing	4	50
	Oral care	3	37,5
	Washing hands	3	37,5
Community living	Domestic skills	2	25
Total		31	

Social Interaction and Adaptation

Social interaction and adaptation skill, which is one of the distinctive features of diagnosis especially in terms of ASD, occurs as the last theme. It is seen that majority of the parents observe restrictions in adaptation in social settings, inappropriate play skills, and restrictions in social interaction in their children resulted from the severity of disability under this theme. The categories and frequencies regarding social interaction and adaptation are presented in Table 7.

When we look at the perceptions of participants on this theme, Mrs. Ela states her experience in social settings as: *"If we go to the shopping mall with the whole family, we definitely get ashamed…".* Mrs. Ayse expresses the negative effects of social involvement on both herself and her child who makes normal progress as*: "…he has to be stopped; someone has to pay attention to him. His older sister cannot do anything for herself. We only go after him.".* Mr. Hakan emphasizes his personal experience based on the disability in terms of experiences he has in social settings as: *"In the class environment or especially in parks when we put him among other children, he does not act like himself and starts to display behaviors like he is a different child.".*

Table 7.

Social interaction and adaptation theme, categories, and frequencies

Sub-theme	Codes	*f*	%
Social adaptation	Adaptation to social settings	7	87,5
	Play skills	5	62,5
	Interaction restrictions	5	62,5
	Preferring to be alone	3	37,5
	Making friends	2	25
Social rules	Social rules	3	37,5
	Etiquette	1	12,5
Social participation	Independent living	5	62,5
	Perspective of society	3	37,5
	Adult independency	2	25
	Personal security	1	12,5
	Bad relations in the family	1	12,5
Total		31	

Discussion

As a result of this research, a total of six themes as physical difficulties, learning and success, language and communication, daily living skills, social interaction, and social adaptation occurred within the scope of parents' perceptions regarding the severity of disability. While some of the findings corresponded to the related researches, differences were observed at some points.

In the literature, there are researches through which findings regarding the problem behaviors of the individuals with a developmental disability and related variables are reported (Webster Stratton and Hammond, 1988; Konstantareas and Homatidis, 1989; Baker et al., 2003, Hastings et al., 2005; Griffith et al., 2010; Colavita, Luthra, and Perry, 2014). It is seen that parents of children diagnosed with ASD within the developmental disability groups reported more problematic behaviors. It is even seen that this situation impedes positive perceptions (Griffith et al., 2010). In this study, it is seen that parents reported problem behaviors regardless of the disability group and that they associated this situation with the severity of disability. Similarly, in the interviews conducted with parents, skill deficits, which threaten the safety of children, were emphasized among the main cases that cause them difficulties (Colavita, Luthra and Perry, 2014). Similarly, the majority of parents (*n=6*) stated that their children act uncontrollably in this study, too.

Restricted and repetitive behaviors, which is one of the ASD diagnosis criteria (APA, 2013), occurred in this study, too, as in similar studies. It is seen that certain psychological variables accompany the high level of problem behaviors, which are observed and reported by parents, (Bishop et al., 2007). Although there is a general perspective regarding the nature of restricted behaviors in this study, it is seen that routine dependency, repetitive behaviors, and lack of motivation were emphasized in the previous researches (Colavita, Luthra and Perry, 2014). Even though the findings of the psychological variables of parents were not included in this study, the parents emphasized the repetitive and restricted behaviors under the theme of problem behaviors (*n=3*).

Social interaction skills, which is another ASD diagnosis criteria (APA, 2013), occurred as a frequently emphasized point in this study, too. The majority of the parents *(n=7)* emphasized the social adaptation problems related to the severity of disability in their children. Regardless of the groups of individuals with disabilities, the stated social interaction problems may be evaluated differently from the researches stating that social skill problems between ASD and other groups significantly differ from each other (Griffith et al., 2010). Similarly, Colavita, Luthra and Perry (2014) reported the social interaction under the title of social cognition.

Another finding that occurred at the end of the research is daily living skills. There are some researchers including the

limitations on adaptive skills and psychological variables related to these limitations of parents within the scope of daily living skills (Bishop et al., 2007; Colavita, Luthra and Perry, 2014). Similarly, it is seen that parents emphasized the daily living skills in this study, too. It is seen that the most emphasized skill among these skills *(n=8)* is toileting skills. Similarly, parents stated that their children display limitations regarding this skill at the rate of 14% among the self-care skills (Colavita, Luthra and Perry, 2014).

Another area that was emphasized by parents regarding their children and in which there are restrictions occurred as language and communication skills (Konstantareas and Homatidis, 1989; McStay et al., 2014; Colavita, Luthra and Perry, 2014). It is emphasized that especially the communication area is perceived as an area in which the most difficulties are experienced by parents (Colavita, Luthra and Perry, 2014). Language and communication area occurred as a frequently emphasized area by parents in this study, too.

It is seen that another skill area emphasized by the parents in the literature is cognitive skills (Konstantareas and Homatidis, 1989). Variables such as attention, motivation, and memory are frequently emphasized among cognitive skills (Colavita, Luthra and Perry, 2014). Similarly, it is seen that parents emphasized the variables such as motivation and remembering under the theme of learning and success in this study, too. The frequently emphasized point in this study is the fact that children cannot express themselves. Similarly, findings in which parents stated that their children cannot express themselves at the rate of 50% were reported (Colavita, Luthra and Perry, 2014).

In addition, the temperament of the child occurred as a variable in the conducted studies (Webster Stratton and Hammond, 1988; Kasari and Sigman, 1997; Colavita, Luthra and Perry, 2014). It can be said that the disability reference, which is seen as child-related, similarly occurred in this study, too. However, it can be included that the parents of children with Down Syndrome have a more moderate attitude in terms of temperament (Kasari and Sigman,1997), this group has fewer restrictions in social aspect compared to the ASD, and parents attribute the

problems to their children along with the restrictions, which are more visible together with the ASD.

Finally, parents mentioned about a relation between the physical difficulties and the severity of disability of their children during the research. The glances of children appear as an emphasized point in terms of physical state. It can be said that this finding is similar to the perception of social surroundings and disability, which were emphasized in the previous researches (Hock and Ahmedani, 2012).

Conclusion and Recommendations

In conclusion, physical difficulties, learning and success, language and communication, daily living skills, social interaction, and social adaptation were gathered under a total of six themes regarding the severity of disability of parents of children with disabilities. While the parents frequently emphasized the problem behaviors, they also revealed their perceptions in terms of social interaction. For the further researches, these can be recommended in light of the findings: a) the perceptions of parents of children with other types of disabilities can be analyzed, b) assessment instruments assessing the severity of disability can be developed, c) the relation between the psychological variables and severity of disability of parents can be studied, d) the relation between the ways of perceiving the severity of disability and cultural states can be studied, and finally, e) the situations between the social acceptance and perception of parents can be studied.

Limitations

Data variation constitutes the main limitation of this research. Collecting the data through various ways may be offered as a suggestion to other researches in terms of the limitation.

Conflict of Interest

The authors declare that they have no conflict of interest.

Funding and Ethical Issues

References

Akkök, F., Aşkar, P. ve Karancı, N. (1992). Özürlü bir çocuğa sahip anne-babalardaki stresin yordanması. *Özel Eğitim Dergisi*, *1*(2), 8-12.

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Baker, B. L., Mcintyre, L. L., Blacher, J., Crnic, K., Edelbrock, C. and Low, C. (2003). Pre-school children with and without developmental delay: Behavior problems and parenting stress over time. *Journal of Intellectual Disability Research, 45*(4/5), 217-230. doi: 10.1046/j.1365-2788.2003.00484.x

Berns, R. M. (2010). *Child, family, school, community, socialization and support.* Wadsworth: Cengage Learning.

Bishop, S. L., Richler, J., Cain, A. C. and Lord, C. (2007). Predictors of percieved negative impact in mothers of children with autism spectrum disorder. *American Journal of Mental Retardation, 112*(6), 450-461. doi: 10.1352/0895-8017(2007)112[450:POPNII]2.0.CO;2

Bogdan, R. C., & Biklen, K. S. (2007). *Qualitative research for education: An introduction to theory methods* (5th edition). Boston: Pearson Education, Inc.

Büyüköztürk, Ş., Kılıç Çakmak, E., Akgün, Ö. E., Karadeniz, Ş. ve Demirel, F. (2013). *Bilimsel araştırma yöntemleri* [Scientific research methods] (14th Ed.). Ankara: Pegem.

Centers for Disease Control and Prevention-CDC, (2016). Community report on autism: From the autism and developmental diabilities monitoring network, 11 sites, United States, 2012. MMWR Surveill Summ, 65(3), 1-23.

Colavita, V. A., Luthra, N. and Perry, A. (2014). Strengths and challenges of children with a developmental disability: A qualitative analysis of parent perceptions. *Journal on Developmental Disabilities. 20*(3), 80-87.

Diken, İ. H., Çuhadar, C., Diken, Ö., Arıkan, A., Ünlü, E., Çelik, S., Tomris, G., Tuna, D. M., Bozkurt, S., Günden, U. O. ve Çavuşoğlu, T. (2016). *Okul Öncesi Öğretmenlerine Yönelik Gelişimsel Yetersizlik Türlerinin Tanım ve Özelikleri* [Definition and Characteristics of Developmental Disabilities for Preschool Teachers]. Ankara: Eğiten.

Dovgan, K. N., Nowell, K. P., & Aguilar, J. (2019). Influences on Parent Perceptions of Autism Severity. *Focus on Autism and Other Developmental Disabilities*, *34*(4), 236-245. doi: 10.1177/1088357618815884

Griffith, G. M., Hastings, R. P., Nash, S. and Hill, C. (2010). Using matched groups to explore child behavior problems and maternal well-being in children with down syndrome and autism. *Journal of Autism and Developmental Disorders*, *40*, 610-619. doi: 10.1007/s10803-009-0906-1

Güleç Aslan, Y., Cihan, H. ve Altın, D. (2014). Otizm spektrum bozukluğu tanılı çocuk sahibi annelerin deneyimleri [Living with a child with autism spectrum disorders: Experiences of mothers]. *Elektronik Sosyal Bilimler Dergisi*, *13*(50), 96-111. doi: 10.17755/esosder.41128

Guscia, R., Harries, J., Kirby, N., Nettelbeck, T. and Taplin, J. (2006) Construct and criterion validities of the Service Need Assessment Profile (SNAP): A measure of support for people with disabilities. *Journal of Intellectual and Developmental Disability*, *31*, 148-155. doi: 10.1080/13668250600876442

Hallahan, D. P., Kauffman, J. M. ve Pullen, P. C. (2014). *Exceptional Learners: An Introduction to Special Education* (12th Ed.). Pearson Higher Ed.

Hastings, R. P., Kovshoff, H., Ward, N. J., Espinosa, F. D., Brown, T. and Remington, B. (2005). System analysis stress and positive perception in mother and father of pre-school children with autism. *Journal of Autism and Developmental Disorders, 35*(5), 635-644. doi: 10.1007/s10803-005-0007-8

Heward, W. L., Alber Morgan, S., R. ve Konrad, M. (2017). *Exceptional children: An introduction to special education* (11th

Ed.). Upper Saddle River: Pearson, Education, Inc.

Hock, R., & Ahmedani, B. K. (2012). Parent perceptions of autism severity: Exploring the social ecological context. *Disability and Health Journal*, *5*(4), 298-304. doi: 10.1016/j.dhjo.2012.06.002

Johnson, R. B., & Christensen, L. (2016). *Educational research: Quantitative, qualitative, and mixed approaches* (6th Ed.). SAGE Publications, Inc.

Kasari, C. and Sigman, M. (1997). Linking parental perceptions to interactions in young children with autism. *Journal of Autism and Developmental Disorders, 27*(1), 39-57. doi: 10.1023/a:1025869105208

Kirk, S., Gallagher, J. J. and Coleman, M. R. (2009). *Educating exceptional children* (12th ed.). Boston: Cengage Learning, Inc.

Kissel, S. D. and Nelson, W. M. (2016). Parents' perceptions of the severity of their child's autistic behaviors and differences in parental stress, family functioning, and social support. *Focus on Autism and Other Developmental Disabilities*, *31*(2), 152-160. doi: 10.1371/journal.pone.0186536

Konstantareas, M. M. and Homatidis, S. (1989). Assessing child symptom severity and stress in parents of autistic children. *Journal of Child Psychology and Psychiatry, 30*, 459-470. doi: 10.1111/j.1469-7610.1989.tb00259.x

Kuder, S. J. (2018). *Teaching students with language and communication disabilities* (5th Ed.). Boston MA: Pearson Education, Inc.

Lickenbrock, D. M., Ekas, N. V. and Whitman, T. L. (2011). Feeling good, feeling bad: Influences of maternal perceptions of the child and marital adjustment on well-being in mothers of children with an autism spectrum disorder. *Journal of Autism and Developmental Disorder, 41*, 848-857. doi: 10.1007/s10803-010-1105-9

McStay, R. L., Dissanayake, C., Scheeren, A., Koot, H. M. and Begeer, S. (2014). Parenting stress and autism: The role of age, autism severity, quality of life and problem behaviour of children and adolescents with autism. *Autism, 18*(5), 502-510. doi: 10.1177/1362361313485163

Merriam, S. B. (2009). *Qualitative research: A guide to design and implemention* (2nd Ed.). San Francisco: John Wiley & Sons, Inc.

Morales, G. E. and Lopez, E. O. (2013). *Down syndrome beyond the intellectual disability: Persons with their own emotional world*. New York: Nova Science Publishers, Inc.

Murdock, G. P. (1965). *Social structure* (10th ed.). New York: The Macmillian Company.

Odom, S. L., Horner, R. H., Snell, M. E., & Blacher, J. (2007). The construct of developmental disabilities. In S. L. Odom, R. H. Horner, M. E. Snell, & J. Blacher (Eds.), *Handbook of developmental disabilities* (pp. 3–14). The Guilford Press.

Patton, M. Q. (2014). *Qualitative research & evaluation methods: Integrating theory and practice*. Sage publications.

Punch, K. F. (2013). *Introduction to social research: Quantitative and qualitative approaches*. Sage.

Remler, D. K. and Ryzin, G. G. (2011). *Research methods in practice: Strategies for description and causation.* California: SAGE Publications, Inc.

Selikowitz, M. (2008). *Down Syndrome: The facts* (3th ed.). New York: Oxford University Press

Smith, J. A., Flowers, P. and Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method and research*. London: Sage Publications, Inc.

Türnüklü, A. (2000). Eğitimbilim araştırmalarında etkin olarak kullanılabilecek nitel bir araştırma tekniği: Görüşme. *Kuram ve Uygulamada Eğitim Yönetimi, 6*(4), 543-559.

Webster Stratton, C. and Hammond, M. (1988). Maternal depression and its relationship to life stress, perceptions of child behavior problems, parenting behaviors, and child conduct problems. *Journal of Abnormal Child Psychology*, 16 (3), 299-215. doi: 10.1007/BF00913802

World Health Organization-WHO. (2018). *11th Revision of the International Classification of Diseases.* Retrieved from https://icd.who.int/browse11/l-m/en#/http://id.who.int/icd/entity/437815624

Yıldırım, A., & Şimşek, H. (2016). *Sosyal bilimlerde nitel araştırma yöntemleri [Qualitative research methods in social sciences]* (10th ed.) Ankara: Seçkin.