Interdisciplinary Description of Complex Systems 23(2), 147-158, 2025

INCLUSION OF CHILDREN WITH DOWN SYNDROME IN SOCIAL LIFE: PARENTS' PERCEPTIONS

Vanja Marković, Sandra Kadum* and Sara Crvić

University Juraj Dobrila of Pula, Faculty of Educational Sciences
Pula, Croatia

DOI: 10.7906/indecs.23.2.7
Regular article

Received: 19 February 2024.
Accepted: 10 March 2025.

ABSTRACT

Understanding the position, role and influence of the family, and especially parental perceptions, on the development of a child with Down syndrome is important both for planning support for the child itself and for developing opportunities for parent empowerment, so that they become and remain as stable and active as possible support for their child.

The aim of the research was to analyse the perceptions of parents of children with Down syndrome related, among other things, to the inclusion of their children in social life, considering their cognitive, social and emotional specificities. The measuring instrument designed for the purposes of this research can provide the data necessary to create an individual profile of the family of a child with Down syndrome.

The analysis of the main components has singled out two factors: the factor of parental perception of the possibilities of a child with Down syndrome and the factor of parental perception of the needs of a child with Down syndrome. The analysis showed that parents of children with Down syndrome from the sample have positive perceptions about the possibilities of their child and clearly defined perceptions about the needs of their child. A positive correlation between factors was found.

In this regard, a significant area is covered by the factor of parental perception of the needs of a child with Down syndrome, which indicates the obstacles faced by parents of children with Down syndrome and in which they need to be provided with targeted and systematic support, both by institutions and non-governmental organizations.

KEY WORDS

parenting, child with Down syndrome, perception of possibilities, perception of needs, health

CLASSIFICATION

JEL: I10

*Corresponding author, η: skadum@unipu.hr; -;
I.M. Ronjgova 1, HR – 52 100 Pula, Croatia

INTRODUCTION

Down syndrome (DS) is the most common chromosomal aberration and the most common cause of intellectual disabilities in children [1, 2]. The Report on Persons with Disabilities in the Republic of Croatia [3] states that 2 000 people with Down syndrome currently live there. The estimated prevalence in Croatia is 1,23 per 1000 births, and in Europe 2,2 per 1000 births [4].

In the last few decades, research has revealed some characteristic patterns of functioning in children and young people with DS. Although there are still numerous unanswered questions related to the developmental features of this population, the aforementioned research has enabled a better understanding of the developmental trajectory associated with DS and how this chromosomopathy affects the development in a dynamic and multisystemic sense [5]. This includes specific patterns of strengths and needs in the areas of information processing, social interactions, emotions, expressive language, receptive skills, motor skills and motivation [6, 7]. In addition, the literature in the field of paediatrics indicates the frequent presence of comorbid conditions that require increased health care and interventions and rehabilitation procedures, such as hearing impairment, obstructive sleep apnoea, otitis media, eye disease, congenital heart disease, sleep disorders and others [8, 9]. In addition, families of children with DS often point out a higher financial burden [10-12]. From all of the above, it is expected, and confirmed by research, that parents of children with DS will experience a higher level of stress and a lower quality of life than parents of neurotypical children [2, 13, 14]. Particularly highlighted is the higher level of stress in parents of children with DS who exhibit undesirable behaviours [15], which is more often in this population than in the population of neurotypical children [8, 16]. Parental stress is defined as a set of processes that lead to adverse psychological and physiological reactions resulting from attempts to adapt to the demands of parenting. This is often perceived as negative feelings or beliefs about oneself and the child [17].

The role of parents has always been a great responsibility and placed demands on individuals [18], but also brought changes in their opinion, behaviour and activities. Parents raising children with developmental disabilities exercise their parenting in even more difficult conditions. These conditions are created by new requirements in child care, frequent visits to experts, frequent hospitalizations and examinations, more demanding day care because the child is generally less independent than its peers of typical development, but also an increased need for information and going through the process of coping with the fact that the child is different and the future more uncertain than expected [19]. Each parent will cope with the difficulty of their child in their own way, which depends on several different factors: the personality of the parent, the type, degree and time of occurrence of the difficulty in the child, parental expectations, family relationships, economic and social conditions of the family, the level of parental education and professional support, help from relatives, friends and associations, and parental information [20]. The research conducted [21] has shown that parents of children with disabilities do everything to compensate for the child's difficulties and that their children would not be conspicuous in their behaviour. Consequently, these parents perceive the demands of the parental role as more burdensome than the parents of children of typical development. They also state significantly more often that they cannot cope with the requirements of the parental role. They rate the level of stress under which they live higher, and their health weaker than the parents of children of typical development.

The birth of a child with Down syndrome will affect the family in a number of ways, from their micro-level interactions to their influence on parental perception at the macro level [6, 22]. Likewise, the characteristics of the family will have a significant impact on the child and his development. Nowadays, the family is recognized as the most important context for the development of the child, both in the cognitive and socio-emotional, communication or adaptive areas [23]. In his research, Cunningham [24] focused on two key questions: what is

the impact of a child with DS on the family and what is the impact of the family on the child. In other words, it is important to determine how a child with DS affects the functioning of the family as a system, whether there are and what are the risk and resistance factors in relation to potential stressors. Likewise, it is important to check which family-related factors positively or negatively affect the development and well-being of the child. Although numerous previous studies have focused on the negative consequences and pathological model of parenting a child with DS [24], there is also a discourse in the literature accompanying the phenomenon of the so-called "advantages of Down syndrome". This concept points to the fact that families of children with DS generally encounter fewer adverse effects and show a higher overall level of adaptation compared to families with children with other types of developmental disabilities [12, 22, 25]. Previous research has already shown that a significant part (65-70%) of the family of a child with DS does not experience its existence as a special risk, and the child itself exclusively as a recipient of care, especially when it comes to families of younger children [26]. Also, the diagnosis of DS is in principle clear immediately after the birth of the child, often before. A clear diagnosis, it has been shown, can help some parents cope with negative attitudes [10]. It is important to note that the concept of the "benefits of Down syndrome" has historically been criticized as an attempt to underestimate the difficulties that parents face, however, modern research shows a growing interest in further discovering the strengths and adaptations that have been observed in families of children with DS [12].

Analysis of the literature in this area leads to the conclusion that most studies still show that parents of children with DS show a higher level of stress and a lower level of quality of life than parents of children with typical development [27, 28], but also fewer negative impacts and a higher level of well-being than parents of children with other developmental disabilities, especially with autism spectrum disorder [29, 30]. Also, it has been shown that mothers of children with DS will perceive a higher level of parental stress than fathers [31]. Namely, it is evident that parents in families of children with disabilities are more likely to assume more traditional parental roles than families of children with typical development. Mothers in these families take on more responsibilities related to household chores and childcare, tend to work part-time or leave work to meet the child's care needs [25, 31, 32]. The literature also warns of an increased likelihood of perinatal depression and perinatal anxiety in mothers of children with DS [33]. Few studies have dealt with the specific peculiarities of parenting children with DS. Among them, it is important to point out that Phillips and associates [13] state that mothers of children with DS show more characteristics of a permissive and less authoritative parenting style and are more likely to ignore their child's undesirable behaviours than mothers of neurotypical children.

METHODOLOGY

RESEARCH AIM

The aim of the research was to examine the perception of research participants: parents of children with DS related, among other things, to the inclusion of their children in social life, while respecting their cognitive, social and emotional specificities.

MEASURING INSTRUMENT

The measuring instrument used to collect the data was designed precisely for the purposes of this research. The instrument takes the form of a survey questionnaire and consists of two parts. The first part consists of four independent variables that collected basic data on research participants. The second part of the measuring instrument contains 16 dependent variables. The reliability of the internal approval of the measuring instrument was checked by the Cronbach coefficient α: it was determined to be $\alpha = 0{,}805$, which shows very good reliability and

acceptable internal consistency of the measuring instrument for this sample. Ideally, the Cronbach alpha coefficient must be greater than 0,70 [34], which is satisfied in our case.

SAMPLE

Parents of children with disabilities were approached through a group on the Facebook social network through which, with the approval of the administrator, the Questionnaire was distributed in the form of a Google Forms form and parents were invited to fill it out. During the implementation of the research, the ethical code was fully respected: the research participants were given instructions in writing on how to fill in the questionnaire, the aim of the research was explained, the possibility of withdrawing, without any consequences, from further response, and they were informed of the guaranteed anonymity.

The sample in this study consisted of parents of children with Down syndrome from the Republic of Croatia, 261 of them. The characteristics of the research participants are shown in Table 1.

Table 1 shows that the largest number of participants in the research is female: 245 or 93,9%, and that three (1,1%) respondents did not indicate gender. It is stated in consistency with the findings of other similar studies, in which respondents are mostly mothers [6, 25]. Furthermore,

Table 1. Characteristics of research participants.

Characteristic of the sample		***f***	***f*, %**
Gender of research participants	male	13	5,0
	female	245	93,9
	no answer	3	1,1
	Total	**261**	**100,0**
The moment you found out you had a child with Down syndrome	first trimester of pregnancy	15	5,7
	second trimester of pregnancy	11	4,2
	third trimester of pregnancy	6	2,3
	after delivery	228	87,4
	no data	1	0,4
	Total	**261**	**100,0**
Age at which you had a child with Down syndrome	17 or more but less than 22	16	6,1
	22 or more but less than 27	48	18,4
	27 or more but less than 32	50	19,2
	32 or more but less than 37	78	29,8
	37 or more but less than 42	51	19,5
	42 or more but less than 47	14	5,4
	47 years or more	1	0,4
	I do not have a child with Down syndrome, but a friend of mine has a granddaughter	1	0,4
	I do not have a child with Down syndrome, but I do have a nephew with Down syndrome	1	0,4
	I adopted a child with Down syndrome	1	0,4
	Total	**261**	**100,0**

it is noted that as many as 228 or 87,4% of them learned that they had a child with DS at the time of birth. The largest number of participants in the research received a child with DS in the age interval "32 or more, but less than 37 years": 78 or 29,8% of them. Parents with an interval of "37 or more but less than 42 years" are 51 or 19,5%, and parents with an interval of "27 or more but less than 32 years" are 50 or 19,2%. The following are parents from the interval "22 or more but less than 27 years" of which 48 or, expressed in percentage, 18,4%.

Three research participants, 1,2% of them, do not have their own child with DS: a respondent states "a friend of mine has a grandchild" or "a niece has a child with Down syndrome", or "I adopted a child with Down syndrome".

Table 2 shows the characteristics of children with DS whose parents participated in the research.

Table 2. Characteristics of children with Down syndrome whose parents participated in the study.

Characteristic		***f***	***f*, %**
Gender of the child with Down syndrome	male	152	58,2
	female	108	41,4
	no data	1	0,4
	Total	**261**	**100.0**
Age of child with Down syndrome	less than 5 years old	77	29,5
	from 5 to 15 years old	123	47,1
	from 16 to 25 years old	48	18,4
	from 26 to 35 years old	6	2,3
	from 36 to 45 years old	5	1,9
	more than 45 years old	1	0,4
	deceased	1	0,4
	Total	**261**	**100.0**

RESULTS AND DISCUSSION

Principal Component Analysis is a technique that is very often used to analyse large datasets containing a large number of dimensions/features per observation, increasing the interpretability of the data while preserving the maximum amount of information and enabling the visualization of multidimensional data. During the analysis of the obtained data, in addition to the analysis of the main components, the Varimax method of factor rotation was used. Analysis of descriptive statistical indicators (arithmetic mean, standard deviation, skewness and kurtosis) and correlation analysis (Pearson correlation coefficient) and paired sample of t-test (t-ratio) were performed on the extracted factors. IBM SPSS Statistics 26 statistical software was used in data processing.

The following values were obtained:

- For descriptive statistics
  - arithmetic mean 3,12;
  - standard deviation: 1,144;
  - skewness – four values are positive, indicating that the majority of the results to the left of the arithmetic mean are among the smaller values; the other eight values are negative and indicate that the majority of the results to the right of the arithmetic mean are among the larger values;
  - kurtosis – two values are positive and eleven are negative; kurtosis values that are less than zero, i.e. have a negative sign, indicate that the distribution of results is flatter than the normal distribution, which means that there are more cases at the edges of the curve.

  - The normality of the distribution of the research results was examined using the Kolmogorov-Smirnov normality test: the obtained value is 0,295, with $df = 261$, $p = 0{,}000$. As the signification is $p = 0{,}000 < 0{,}05$, the assumption of the normality of the distribution has not been confirmed, the normality proves to be statistically significant and it is therefore rejected as an unrealistic assumption (which is quite common in large samples).
- For the correlation analysis, the Pearson correlation coefficient is $r = 0{,}252$; the correlation is significant at the level of .01 (two-sided).
- The paired sample of the *t*-test (*t* -ratio) indicates that the smallest value of the *t* -ratio is $t = 26{,}649$, while the largest value is $t = 65{,}129$, both values with $df = 260$ and $p = 0{,}000$.

In order to check whether the application of factor analysis is possible, the prerequisites for its application were examined. It was found that the prerequisites that are important for the application of factor analysis were met. Namely, the number of respondents is satisfactory (261 > 101). The Kaiser-Meyer-Olkin measure of sampling adequacy is $KMO = 0.755$ and is greater than 0,70, which is a satisfactory prerequisite according to Field. Bartlett's test of sphericity, which is $\chi^2 = 335{,}622$, ($df = 66$, $p = 0{,}000 < 0{,}001$) was also satisfied. The number of factors – two of them – was determined using the Kaiser-Gutmann eigenvalues criterion, Horn's parallel analysis and Katel's landslide test.

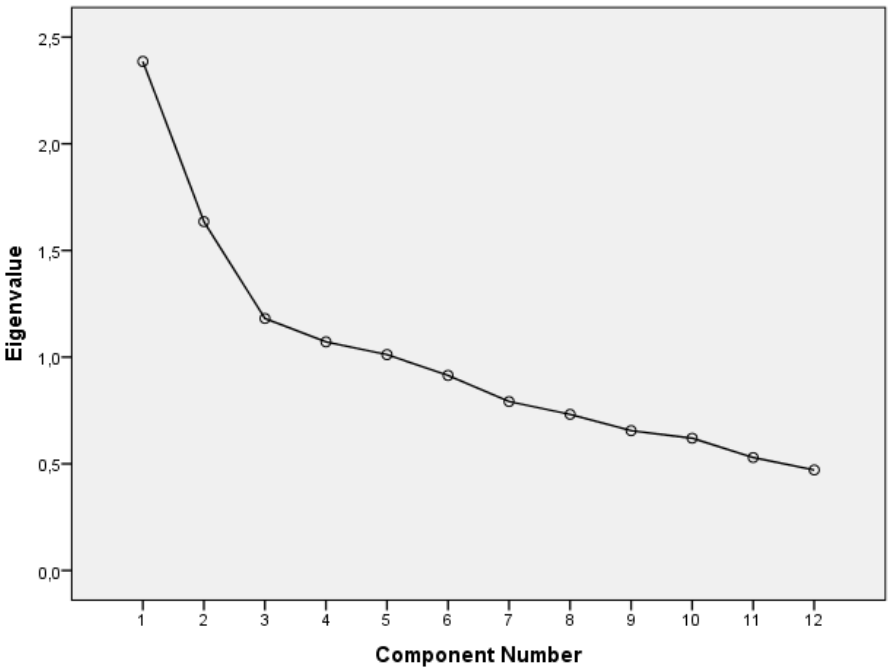

Figure 1. Pass Diagram.

From the pass diagram (Figure 1), the diagram break at the junction of the second and third components is quite clear. Components 1 and 2, which are above the inflection point, explain much more of the variance than the remaining components; therefore, we will dwell on two components, i.e., we will single out two factors. This is shown in the component matrix in Table 3.

Table 3 shows that the five items of the first component have sufficiently large factor weights: above 0,4, while only two items have a value of less than 0,4; in the second component, all items, three of them, have factor weights above 0,4. In the third component, only one paragraph is larger than .4, while the other three are smaller, and in the fourth component we have only one item and it is larger than .4. This tells us that a two-factor solution is appropriate.

Table 3. Component Matrix. Extraction method: analysis of the main components. Five extracted components.

	Component				
	1 (PM)	**2 (PO)**	**3**	**4**	**5**
My life is no different because I have a child with Down syndrome	0,742				
When I have to do something for myself, I have a place to leave my child.	0,655				
My child has the same opportunities for development as any other child	0,651				
My child has access to various organised activities outside kindergarten / school.	0,627				
Family members responded positively to my child with Down syndrome.	0,487		–0,484		
Already in kindergarten, more education on diversity should be introduced		0,727			
Because of the needs of my child with Down syndrome, we have more expenses than other families.		0,642			
Adults are prejudiced about children with Down syndrome.		0,611	0,366		
My child is accepted by peers in kindergarten / school.	0,335		–0,544	0,427	
What is the reaction of other children in the family to a brother / sister with Down syndrome?			0,504	0,487	
My child with Down syndrome was (or is currently) involved in early intervention procedures.				0,685	
When I found out about the child's difficulty, I wanted to terminate the pregnancy.	–0,305				0,818

With these two factors, 37,5% of the total variance is explained, of which 21,9% refers to the first factor, and 15,6% to the second factor of the variance of the examined phenomenon.

The extracted factors are named as follows:

first factor: parental perception of the possibility of a child with DS (PM),
second factor: parental perception of the needs of a child with DS (EE).

Table 3 shows that the *PM* factor includes seven dependent variables related to parental perception of the possibilities of a child with Down syndrome and that the *PO* factor includes three dependent variables related to parental perception of the needs of a child with DS.

The statistical indicators presented in Table 4 show that the participants in the research have positive perceptions about the possibilities of a child with DS (PR) $M = 3,24$, $SD = 1,193$, and clearly defined perceptions about the needs of a child with DS (PO): $M = 3,93$, $SD = 1,103$.

Table 4. Descriptive statistics and correlation between extracted factors. PM – parental perception of the possibility of a child with Down syndrome, PO – parental perception of the needs of a child with Down syndrome, *M* – arithmetic mean; SD – standard deviation, Corr. coeff. – Pearson correlation coefficient, *t* – t-ratio; *p* – statistical significance

Factor	***M***	***SD***	***Skewness***	***Kurtosis***	***Corr. coeff.***		***t***	***p***
PM	3,24	1,193	–0,651	–0,925	1	0,277**	1,06	0,000
PO	3,93	1,103	–1,255	1,449	0,227**	1		

**statistically significant at level 0,01

Correlation between factors is positive, amounts to 0,227 and is statistically significant at the level of significance 0,01. The values of the form of distributions (skewness and kurtosis) indicate certain deviations from the values inherent in the normal distribution of data. The calculated *t*-ratio is 1,06 ($p = 0{,}000 < 0{,}01$), and such a low *t* -ratio value indicates that the conclusion on the verification of the null hypothesis is justified: There is not enough justification for the claim that there would be a difference found in case of examining all parents from the group from which the participants in this research were selected. There is evidence that parents often negatively perceive their children with disabilities, which is accompanied by feelings of pessimism, guilt, rejection, and even shame [10, 35]. A study conducted in Ukraine showed that almost 50% of parents of children with disabilities show a tendency to emotionally distance themselves from their child [36]. However, a review of contemporary research presented, among others, by Ghojavand and Ghojavand [37] shows that there is an increasingly widespread consensus that multiple challenges associated with parenting a child with DS do not necessarily lead to negative perceptions in the family.

PM and PO factors were singled out based on the responses of research participants – parents of children with DS, and were recognized as positive perceptions of the abilities of a child with DS and a clearly defined perception of the needs of a child with DS related, among other things, to the inclusion of their children in social life, considering their cognitive, social and emotional specifics. The perspective related to parenting a child with DS has changed significantly over the decades [11, 38], as evidenced by the findings of this research. The results build on a French research [39] which showed that parents generally love and accept their child with DS (99% of parents), are proud of it (98% of parents), and that their own outlook on life is more positive because they have a daughter or son with DS (78% of parents). A similar, positive perception of the child's abilities, especially among parents who had a child with DS at an older age, was shown by a study conducted by Eddaoudi et al. [40]. The results of this research can be compared, among other things, with the data obtained by Siklos and Kerns [41], who found that parents of children with DS perceive the inclusion in the community and friendship opportunities as the greatest needs of their child, unlike parents of children with autism spectrum disorder, who perceive the needs related to professional support for the child and family as the most important for their child. The parental perception of the needs related to the increased costs of the family of a child with DS was also confirmed by other studies [10-12, 42].

CONCLUSION

A subjective experience of parenting that is based on positive assessments in the child will encourage and develop emotional security, independence, social competencies and a higher level of intellectual achievement. On the other hand, the experience of parenting based on negative assessments can encourage parents to be insensitive to the needs of the child, but also to be aggressive and prone to punishment, which can significantly jeopardize the development of the child and lead to negative consequences for his behaviour and development [43]. The level of parental stress will depend, among other things, on the characteristics of the child, which include the type of developmental disability [44]. Realistic assessments of the functioning of a child with DS by parents can help, among other things, to create better support and counselling work [45]. Understanding the position, role and influence of the family, and especially parental perceptions, on the development of a child with Down syndrome is important both for planning support for the child itself and for developing opportunities for parent empowerment, so that they become and remain as stable and active as possible support for their child. Recently, a large number of studies have focused on the families of children with disabilities, and the results of these studies indicate the growing need of families for help and support, both by members of their immediate and extended families, as well as the social community in which they live. The need to design a support program based on the individual

profile of the family is emphasized, based on the perception of the strengths and needs of the family, through which targeted support for the child and the family will be provided [46, 47]. A measuring instrument designed for the purposes of this research can provide the data necessary to create an individual profile of the family of a child with DS. In this regard, a significant area is covered by the PO factor (the factor of parental perception of the needs of a child with DS), which indicates the obstacles faced by parents of children with DS and in which they need to be provided with targeted and systematic support, both by institutions and non-governmental organizations.

The limitations of this paper can also serve as suggestions for further research that is necessary in the field of parental perception of the opportunities and needs of children with DS. The national character of the sample in this study may limit the generalization of the results. Further research could show whether the results can also be generalized to other samples and environments. Also, further research into the perception of opportunities and needs could focus on factors such as the financial capabilities of the family, the gender of the parents, the level of support available in the community, and the like. Also, further research should certainly, in addition to quantitative, include qualitative methods, in order to gain a more comprehensive insight into parental perception and other peculiarities of the parent-child relationship with Down syndrome and to enable targeted and individualized support, as previously emphasized.

REFERENCES

[1] Davis, A.S.: *Children with down syndrome: Implications for assessment and intervention in the school.*
School Psychology Quarterly **23**(2), 271-281, 2008,
http://dx.doi.org/10.1037/1045-3830.23.2.271,

[2] Fucà, E.; Costanzo, F.; Ursumando, L. and Vicari, S.: *Parenting Stress in Mothers of Children and Adolescents with Down Syndrome.*
Journal of Clinical Medicine **11**(5), No. 1188, 2022,
http://dx.doi.org/10.3390/jcm11051188,

[3] Benjak, T.: *Report on persons with disabilities in the Republic of Croatia*. In Croatian.
Hrvatski zavod za javno zdravstvo, Zagreb, 2023,
https://www.hzjz.hr/wp-content/uploads/2023/09/Izvjesce_o_osobama_s_invaliditetom_2023-1.pdf,

[4] Tomac, V., et al.: *Epidemiological, cytogenetic and clinical characteristics of children with Down syndrome in eastern Croatia – fifteen-year postnatal experience.* In Croatian.
Paediatria Croatica **65**(2), 67-73, 2021,
http://dx.doi.org/10.13112/PC.2021.11,

[5] Fidler, D.J. and Nadel, L.: *Education and children with Down syndrome: Neuroscience, development, and intervention.*
Mental Retardation and Developmental Disabilities Research Reviews **13**(3), 262-271, 2007,
http://dx.doi.org/10.1002/mrdd.20166,

[6] Cuskelly, M.; Hauser-Cram, P. and Van Riper, M.: *Families of children with Down syndrome: What we know and what we need to know.*
Down's Syndrome, Research and Practice **12**(3), 202-210, 2009,

[7] Škrbina, D.: *Foster Familly Support for Child with Down Syndrome*. In Croatian.
Život i škola: časopis za teoriju i praksu odgoja i obrazovanja **23**(1), 9-34, 2010,

[8] Feeley, K, and Jones, E.: *Strategies to address challenging behaviour in young children with Down syndrome.*
Down Syndrome Research and Practice **12**(2), 153-163, 2007,
http://dx.doi.org/10.3104/case-studies.2008,

[9] Bull, M.J.: *Health Supervision for Children With Down.*
Pediatrics **128**(2), 393-406, 2011,
http://dx.doi.org/10.1542/peds.2011-1605,

[10] Bywaters, P.; Ali, Z.; Fazil, Q.; Wallace, L.M. and Singh, G.: *Attitudes towards disability amongst Pakistani and Bangladeshi parents of disabled children in the UK: considerations for service providers and the disability movement.*
Health & Social Care in the Community **11**(6), 502-509, 2003,
http://dx.doi.org/10.1046/j.1365-2524.2003.00456.x,

[11] Durmaz, A., et al.: *Interview with parents of children with Down syndrome: their perceptions and feelings.*
The Indian Journal of Pediatrics **78**, 698-702, 2011,

[12] Desimpelaere, E.N.; De Clercq, L.E.; Soenens, B.; Prinzie, P. and De Pauw, S.S.: *Parenting a child with Down syndrome: A qualitative study on parents' experiences and behaviors from a self determination theory perspective.*
Journal of Pediatric Nursing **74**, 14-27, 2024,
http://dx.doi.org/10.1016/j.pedn.2023.10.021,

[13] Phillips, B.A.; Conners, F. and Curtner-Smith, M.E.: *Parenting children with Down syndrome: An analysis of parenting styles, parenting dimensions, and parental stress*.
Research in Developmental Disabilities **68**, 9-19, 2017,
http://dx.doi.org/10.1016/j.ridd.2017.06.010,

[14] Darla, S. and Bhat, D.: *Health-related quality of life and coping strategies among families with Down syndrome children in South India.*
Medical Journal Armed Forces India **77**(2), 187-193, 2021,
http://dx.doi.org/10.1016/j.mjafi.2020.07.010,

[15] Norizan, A. and Shamsuddin, K.: *Predictors of parenting stress among Malaysian mothers of children with Down syndrome.*
Journal of Intellectual Disability Research **54**(11), 992-1003, 2010,
http://dx.doi.org/10.1111/j.1365-2788.2010.01324.x,

[16] Van Gameren-Oosterom, H.B., et al.: *Development, problem behavior, and quality of life in a population based sample of eight-year-old children with Down syndrome*.
PloS One **6**(7), No. e21879, 2011,
http://dx.doi.org/10.1371/journal.pone.0021879,

[17] Deater-Deckard, K.: *Parenting Stress*.
Yale University Press, New Haven, 2004,

[18] Matoš, D., et al.: *Let us grow together*. In Croatian.
Dijete, vrtić, obitelj **15**(57), 10-12, 2009,

[19] Ljubešić, M.: *Podrška roditeljima djece s teškoćama u razvoju*.
In: Starc, B., ed.: Roditeljstvo u najboljem interesu djeteta i podrška roditeljima najmlađe djece s teškoćama u razvoju.UNICEF, Zagreb, pp.16-24, 2004,

[20] Leutar, Z. and Štambuk, A.: *Disability Within Family and Sources of Support*. In Croatian.
Hrvatska revija za rehabilitacijska istraživanja **43**(1), 47-61, 2007,

[21] Ljubešić, M.: *Parent and the child with disabilities*. In Croatian.
In: Pećnik, N., ed.: Kako roditelji i zajednice brinu o djeci najmlađe dobi u Hrvatskoj. Ured UNICEF-a za Hrvatsku, pp.84-97, 2013,

[22] Hodapp, R.M.: *Families of persons with Down syndrome: New perspectives, findings, and research and service needs.*
Mental Retardation and Developmental Disabilities **13**, 279-287, 2013,
http://dx.doi.org/10.1002/mrdd.20160,

[23] Hauser-Cram, P., et al.: *Family influences on adaptive development in young children with Down syndrome.*
Child Development **70**(4), 979-989, 1999,

[24] Cunningham, C.: *Families of children with Down syndrome*.
Down Syndrome Research and Practice **4**(3), 87-95, 1996,
http://dx.doi.org/10.3104/perspectives.66,

[25] Brown, R.I.; MacAdam-Crisp, J.; Wang, M. and Iarocci, G.: *Family quality of life when there is a child with a developmental disability*.
Journal of Policy and Practice in Intellectual Disabilities **3**(4), 238-245, 2006,

[26] Sloper, P. and Turner, S.: *Risk and resistance factors in the adaptation of parents of children with severe physical disability.*
Journal of Child Psychology and Psychiatry **34**(2), 167-188, 1993,
http://dx.doi.org/10.1111/j.1469-7610.1993.tb00978.x,
[27] Hedov, G.; Anneren, G. and Wikblad, K.: *Swedish parents of children with Down's syndrome: Parental stress and sense of coherence in relation to employment rate and time spent in child care.*
Scandinavian Journal of Caring Sciences **16**(4), 424-430, 2002,
[28] Scott, B.S.; Atkinson, L.; Minton, H.L. and Bowman, T.: *Psychological distress of parents of infants with Down syndrome.*
American Journal on Mental Retardation **102**(2), 161-171, 1997,
http://dx.doi.org/10.1352/0895-8017(1997)102<0161:PDOPOI>2.0.CO;2,
[29] Abbeduto, L., et al.: *Psychological well-being and coping in mothers of youths with autism, Down syndrome, or fragile X syndrome.*
American Journal on Mental Retardation **109**(3), 237-254, 2004,
[30] Pisula, E.: *A comparative study of stress profiles in mothers of children with autism and those of children with Down's syndrome*.
Journal of Applied Research in Intellectual Disabilities **20**(3), 274-278, 2007,
[31] Dündar, A. and Yetiş, Ü.: *Investigation of despair levels of families with Down syndrome child and their parental attitudes on perception and coping with stress (City of Adiyaman example).*
Turkish Studies**14**(1), 279-290, 2019,
http://dx.doi.org/10.7827/TurkishStudies.14970,
[32] Vatne, T.M.; Dahle, S.S.; Haukeland, Y.B. and Fjermestad, K.W.: *A Qualitative Study of Men's Experience of Being a Father in Families with Childhood Disability.*
Journal of Developmental and Physical Disabilities **35**, 111-131, 2023,
http://dx.doi.org/10.1007/s10882-022-09847-8,
[33] Kammes, R.R.; Lachmar, E.M.; Douglas, S.N. and Schultheiss, H.: *"Life-altering": A qualitative analysis of social media birth stories from mothers of children with Down syndrome.*
Journal of Intellectual Disabilities **26**(4), 919-937, 2022,
http://dx.doi.org/10.1177/17446295211025960,
[34] DeVellis, R.F.: *Scale development: Theory and applications.*
Sage, Thousand Oaks, 2012,
[35] Batool, H.; Khan, A.M. and Ashraf, S.: *An analysis of attitude of parents towards children with intellectual disability*.
Journal of Early Childhood Care and Education **2**, 21-34, 2018,
[36] Suhonos, O.S.: *Parent-child relations in families that bring up down syndrome children.*
Journal of Education, Health and Sport **11**(11), 91-99, 2021,
http://dx.doi.org/10.12775/JEHS.2021.11.11.008,
[37] Ghojavand, Z. and Ghojavand, G.: *Parental attitude and adjustment towards children with Down syndrome: A comparative study.*
International Journal of Education and Psychology in the Community **2**(2), 20-32, 2012,
[38] Hodapp, R.M. and Ly, T.M.: *Parenting children with developmental disabilities*.
Routledge, 2006,
[39] Bertrand, R.: *Parents' perspective on having a child with Down Syndrome in France*.
American Journal of Medical Genetics Part A **179**(5), 770-781, 2019,
[40] Eddaoudi, S., et al.: *Challenges and Concerns of Parents with Children with Down Syndrome.*
Mental Health **7**, 15-17, 2023,
[41] Siklos, S. and Kerns, K.A.: *Assessing need for social support in parents of children with autism and Down syndrome.*
Journal of Autism and Developmental Disorders **36,** 921-933, 2006,

[42] Caldwell, A.R., et al.: *Parental perception of facilitators and barriers to health among young children with Down syndrome: a qualitative study*.
Frontiers in Pediatrics **11**, No. 1155850, 2023,
http://dx.doi.org/10.3389/fped.2023.1155850,

[43] Čudina Obradović, M. and Obradović, J.: *Support to Parenthood: Challenges and Possibilities*.
Revija za socijalnu politiku **10**(1), 45-68, 2003,

[44] Andrés-Romero, M.P.; Flujas-Contreras, J.M.; Fernández-Torres, M.; Gómez-Becerra, I. and Sánchez-López, P.: *Analysis of psychosocial adjustment in the family during confinement: Problems and habits of children and youth and parental stress and resilience.*
Frontiers in Psychology **12**, No. 647645, 2021,
http://dx.doi.org/10.3389/fpsyg.2021.647645,

[45] De Graaf, G.; Levine, S.P.; Goldstein, R. and Skotko, B.G.: *Parents' perceptions of functional abilities in people with Down syndrome*.
American Journal of Medical Genetics Part A **179**(2), 161-176, 2019,
http://dx.doi.org/10.1002/ajmg.a.61004,

[46] Bulić, D.; Joković Oreb, I. and Nikolić, B.: *Mothers' Involvement in Everyday Activities of Children with Developmental Disabilities*. In Croatian.
Hrvatska revija za rehabilitacijska istraživanja **48**(2), 1-12, 2012,

[47] Van Heumen, L. and Schippers, A.: *Quality of life for young adults with intellectual disability following individualised support: Individual and family responses*.
Journal of Intellectual & Developmental Disability **41**(4), 299-310, 2016,
http://dx.doi.org/10.3109/13668250.2016.1213797.