

Relationship between loneliness, hopelessness and social support experienced by mothers with disabled children

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Abstract

The aim of the study was to evaluate the relationship between loneliness, hopelessness and social support experienced by mothers with disabled children. This cross-sectional study was conducted with 106 mothers with disabled children. The data was collected by compiling the Personal Information Form and by applying three main scales: the UCLA Loneliness Scale (UCLA-LS), the Beck Hopelessness Scale (BHS) and the Multidimensional Scale of Perceived Social Support (MSPSS). The data obtained was analyzed using the number, percentage, mean, correlation, T test, Anova and Mann Whitney U tests. The UCLA-LS mean score of the mothers was 50.56 ± 11.94 , the BHS mean score was 10.78 ± 4.93 and the MSPSS mean score was 40.97 ± 13.86 . The results showed a

Received: July 19, 2022; Revised: March 24, 2023; Accepted: May 19, 2023

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Conflict of interest: The authors report no conflicts of interest.

Ethical Approval: Ethical approval was granted by Munzur University (the approval code: 7795 / 30603717-050.01.04-meeting number: 3, decision number: 20).

Funding: The study was supported by the Scientific Research Projects Coordination Unit of Munzur University (Project Code: MFMUB018-10).

Acknowledgements: Authors express their thanks to MUNIBAP and the women who participated in the study.

positive correlation between the mean scores of the loneliness and hopelessness scale, and a negative correlation between the mean scores of the loneliness and hopelessness scale and the mean MSPSS score ($p < .05$). As a result of the research findings, mothers with disabled children experienced loneliness and hopelessness and did not receive sufficient social support.

Keywords: Child; Disability; Hopelessness; Loneliness; Social support.

1. Introduction

Disability is defined as “the inability to perform functions that are normal for children due to impairment or handicap, which may be influenced by age, gender, social, and cultural factors” (Kaçan Softa, 2013). Together with the increase in chronic diseases among the elderly population worldwide, there has been a rise in the disability rates resulting from health, environmental, and other factors, such as traffic accidents and natural disasters. As results from the literature, the disability rate, which was reported as 10% by the World Health Organization (WHO) in the 1970s, increased to 15% in 2011 (Işık, Tastan, Temur, Kara, & Mısırlıoğlu, 2011; Şentürk & Varol-Saraçoğlu, 2013). According to WHO (2009), there are approximately 650 million disabled people worldwide, with 700,000 to 1.5 million of them being intellectually disabled individuals. Results from a 2002 study conducted by the Turkish Statistical Institute and Prime Ministry Department of the Administration of the Disabled showed that 12.29% of the total population in Turkey is disabled (Işık *et al.*, 2011; Şentürk & Varol-Saraçoğlu, 2013). Of these individuals, 29.4% were reported to be intellectually disabled (Balcı, Kızıl, Savaşer, Dur, & Mutlu, 2019). The increase in disability rates leads to physical, economic, and psychosocial problems.

When parents decide to have children, they typically hope for a healthy child. The anticipation of a child with normal characteristics, along with hopes, expectations, and plans for the future, can make the birth of a child with different characteristics very challenging for the family’s psychological well-being and their relationships with the social environment (Kumar, 2008; O’Keeffe & O’Hara, 2008; Köksal & Kabasakal, 2012; Beşer & İnci, 2014; Yılmaz, 2020). Studies reported that mothers usually take care of disabled children and play a more active role in managing these challenges (Telci, Yarar, Cavlak, & Atalay, 2018). Mothers try to adapt to these changes, to search for solutions to the situation, and often suffer from anxiety due to uncertainty about what will happen and what to do. Additionally, they may experience feelings of shock, rejection, suffering, depression, guilt, and embarrassment (S’lungile, Ntinda, & Hylanze, 2015; Balcı *et al.*, 2019; Yaşar & Bıçakçı, 2019). Studies conducted in Turkey and abroad indicated that mothers of children with disabilities experience psychological problems, such as anxiety, stress, disruption in family functioning, negative effects on life satisfaction, and depression (Ceylan & Aral, 2007; Beşer & İnci, 2014; S’lungile *et al.*, 2015; Yılmaz, 2020).

Research has also shown that the child's dependence on their mother increases the burden on mothers and the thought that their children may not be able to recover can negatively impact their future expectations (Işık *et al.*, 2011; Crettenden, Lam, & Denson, 2018). Consequently, mothers with disabled children were reported to experience a higher level of hopelessness, insufficient social support (Aldosarı & Pufpaff, 2014; Ciğerli, Topsever, Alvir, & Görpelioğlu, 2014), and a greater sense of loneliness (Tsai & Wang, 2009; Yıldırım, Aşilar, & Karakurt, 2012; Gosztyła & Prokopiak, 2017).

Health professionals who work with disabled children and their families have a crucial responsibility. In this respect, nurses play a significant role in identifying the challenges that mothers of disabled children face. Research has shown that the support provided by health professionals to mothers of children with disabilities is effective in increasing their knowledge, in facilitating the interaction with their children, and in adopting problem-focused coping strategies for the care of their children (Yıldırım *et al.*, 2012). Therefore, supporting mothers becomes essential to identify the challenges they face and to empower them.

The aim of the study conducted was thus to evaluate the relationship between loneliness, hopelessness and social support experienced by mothers with disabled children.

2. Methods

2.1. Design

The study conducted was a cross-sectional study.

2.2. Population and sample

The research was conducted between January 2019 and January 2020 in a province in the eastern region of Turkey with mothers of disabled children attending a private Special Education Center in the city center. This center is the only one in the province providing services to children with disabilities. All children enrolled at this center presented learning difficulties, ranging from mild to severe. As the population size was relatively small, we decided to include all the mothers of disabled children enrolled at the center (N = 156). However, only 125 mothers agreed to participate in the study voluntarily. Of these, 19 were excluded since 10 mothers decided not to

continue participating and 9 compiled data forms that were incomplete. Therefore, the final sample included 106 mothers of intellectually disabled children, which accounted for 68% of the population.

2.3. Data collection tools

The “Personal Information Form”, the “UCLA Loneliness Scale”, the “Beck Hopelessness Scale” and the “Multidimensional Scale of Perceived Social Support” were used for the data collection in this study.

2.3.1. The Personal Information Form

It is a form developed by researchers and consists of 10 questions focused on evaluating the basic characteristics of children with disabilities and their mothers.

2.3.2. The UCLA Loneliness Scale (UCLA-LS)

Russell (1996) developed the scale and the Turkish adaptation was made by Demir (1989). The UCLA-LS, which was developed to measure overall loneliness, consists of a total of 20 questions, which are coded as 10 positively worded and 10 negatively worded. Questions are set in 4-point Likert scale categories, the lowest score corresponding to 20 and the highest score to 80. In this scale, loneliness increases as the score from the scale increases. In this study, Cronbach’s alpha was calculated as .79.

2.3.3. The Beck Hopelessness Scale (BHS)

The validity and reliability of the scale was developed by Beck and colleagues (Beck, Weissman, Lester, & Trexler, 1974). The reliability and validity of the Turkish version of the BHS was instead conducted by Durak (1994) and Seber and co-workers (Seber, Dilbaz, Kaptanoğlu, & Tekin, 1993) who calculated Cronbach’s alpha coefficient as .86. The scale consists of 20 true-false statements with 11 correct and 9 incorrect answer keys. 1 point is given for each response compatible with the key, and 0 points are given for each incompatible answer. The lowest score obtained from the scale is 0, and the highest score is 20. The evaluation of the scores obtained from the scale are the following: 0-3 points no hopelessness, 4-8 points mild hopelessness, 9-14 points moderate hopelessness and 15-20 points severe hopelessness. Thus, higher scores on the scale indicate increased hopelessness for the individual. In this study, Cronbach’s alpha coefficient of the scale was calculated as .84.

2.3.4. The Multidimensional Scale of Perceived Social Support (MSPSS)

It was developed by Zimet and colleagues (Zimet, Dahlem, Zimet, & Farley, 1988). The reliability and validity of the Turkish version of the MSPSS was conducted instead by Eker and co-workers (Eker, Arkar, & Yaldız 2001). Cronbach's alpha coefficient of the MSPSS was reported as $\alpha = .89$. The MSPSS consists of a 12-item scale, developed in 7-point Likert categories, that aims to individually evaluate the adequacy of social support from three different sources. Each source consists of four items and includes three subgroups regarding the source of social support from family, friends and significant other source. The subscale score is obtained by summing the scores of the four items in each subscale, and the total score of the scale is obtained by summing all subscale scores. The lowest score that can be obtained from the subscales is 4, and the highest score is 28. The lowest score that can be obtained from the entire scale is 12 and the highest score is 84. As the score obtained from the scale increases, the social support perceived also increases. In this study, Cronbach's alpha coefficient of the scale was calculated as .88.

2.4. Data collection

The data of the study was collected from mothers with disabled children, using face-to-face interviews lasting on average 25-30 minutes, by interviewers who had experience working with disabled people.

2.5. Data analysis

The data obtained in the study was transferred to a computer-aided database and evaluated with numbers, percentages, mean, correlation, T-test, Anova and Mann Whitney-U tests.

2.6. Ethical dimension

An Ethics committee approval (E.7795 / 30603717-050.01.04-) was obtained from the Munzur University Non-Interventional Ethics Committee on 16.05.2018 to conduct the study. The mothers included in the study were informed about the purpose of the study following the Helsinki Declaration. They were also informed that the data collected was only used for scientific purposes, and that the identity and information concerning the children were not used elsewhere and were kept confidential. In addition, it was

established that the mothers' participation in the study was voluntary and they had the right to leave the study at any time. Mothers were not forced to participate in the study in any way.

3. Results

The mean age of the mothers was 48.99 ± 12.58 years old. Most of the mothers (96.2%) reported they had no form of employment, 55.7% did not have any social security, and 81.2% found that their income was less than their expenses (see Tab. 1 for more details).

Table 1 – *Distribution of the descriptive features of mother and children (N = 106)*

Features	<i>n</i>	%
Mother's age	48.99 ± 12.58	
Educational level		
Illiterate	32	30.2
Middle school	51	48.1
High school and higher	23	21.7
Employment status		
Yes	4	3.8
No	102	96.2
Social security		
Yes	47	44.3
No	59	55.7
Socioeconomic status		
Income is less than expenses	86	81.2
Income equals expenses	20	18.8
Family type		
Nuclear	87	82.1
Extended	19	17.9
Number of children	3.03 ± 1.57	
Child's age	18.76 ± 11.31	
Birth order of the child	2.27 ± 1.47	
Gender of the child		
Girl	49	46.2
Boy	57	53.8
Degree of disability		
Mild	44	41.5
Moderate	50	47.2
Severe	12	11.3

Moreover, 82.1% of the mothers in nuclear families had an average of 3.03 ± 1.57 children. The mean age of the children was 18.76 ± 11.31 years old and 53.8% of them were boys. Among the children, 47.2% had moderate intellectual disabilities, and on average, these children were 2.27 ± 1.47 per family (Tab. 1).

The mean score of the UCLA LS of the mothers was 50.56 ± 11.94 and the mean BHS score was 10.78 ± 4.93 (refer to Tab. 2). The BHS score of the mothers was considered in the moderate range. The mothers' mean score of perceived social support was 40.97 ± 13.86 . When the three subscales were considered, the mean MSPSS score from the family subscale was 15.77 ± 5.92 , the mean MSPSS score from the friend subscale was 12.10 ± 4.11 , while the MSPSS score from the significant other subscale was 13.09 ± 5.15 points (see Tab. 2 for more details).

Table 2 – *Distribution of mean scores regarding mothers' UCLA Loneliness Scale, Beck Hopelessness Scale and the Multidimensional Scale of Perceived Social Support*

Scale	<i>M</i> ± <i>SD</i>	<i>Min-Max</i>
UCLA-LS	50.56 ± 11.94	23-80
BHS	10.78 ± 4.93	1-19
Total MSPSS	40.97 ± 13.86	15-80
MSPSS Family	15.77 ± 5.92	5-28
MSPSS Friend	12.10 ± 4.11	4-28
MSPSS significant other	13.09 ± 5.15	4-26

When the level of the mothers' education was taken in consideration, the UCLA LS mean score was found to be inversely related to the degree of education. In fact, the score was higher in illiterate mothers (54.30 ± 13.10), followed by mothers with a primary-secondary school education (48.68 ± 9.86) and by mothers with a high school or higher education (41.43 ± 15.06 ; refer to Tab. 3 for more details). A similar trend was found for non-working mothers (51.26 ± 11.61) vs working mothers (33.25 ± 9.17), mothers with an extended family type (53.36 ± 10.43) vs mothers with a nuclear family type (49.82 ± 12.20), mothers without social security (52.42 ± 10.27) vs mothers with social security (48.00 ± 13.46) and mothers whose income was less than their expenses (52.36 ± 10.96) vs mothers whose income was equals to their expenses (42.30 ± 12.79 ; see Tab. 3 for more details).

Table 3 – *UCLA LS, BHS and MSPSS mean score distribution according to the descriptive features of mothers*

Features	UCLA LS <i>M ± SD</i>	BHS <i>M ± SD</i>	MSPSS <i>M ± SD</i>
Educational level			
Illiterate	54.30 ± 13.10	12.09 ± 5.25	41.03 ± 14.31
Middle school	48.68 ± 9.86	10.96 ± 4.48	40.72 ± 13.26
High school and higher	41.43 ± 15.06	8.52 ± 4.82	41.43 ± 15.06
Test	<i>F</i> = 2.55, <i>p</i> = .08	<i>F</i> = 3.80, <i>p</i> = .02	<i>F</i> = 0.21, <i>p</i> = .97
Employment status			
Yes	33.25 ± 9.17	2.50 ± 1.00	59.50 ± 17.40
No	51.26 ± 11.61	11.09 ± 4.76	40.24 ± 13.29
Test	<i>U</i> : 35.50, <i>p</i> = .002	<i>U</i> : 23.50, <i>p</i> = .003	<i>U</i> : 68.50, <i>p</i> = .025
Family type			
Nuclear	49.82 ± 12.20	10.36 ± 4.95	41.97 ± 14.20
Extended	53.36 ± 10.43	12.68 ± 4.48	36.36 ± 11.37
Test	<i>U</i> : 694.50, <i>p</i> = .27	<i>U</i> : 601.50, <i>p</i> = .063	<i>U</i> : 658.50, <i>p</i> = .16
Social security			
Yes	48.00 ± 13.46	9.00 ± 5.09	45.85 ± 15.05
No	52.42 ± 10.27	12.20 ± 4.34	37.08 ± 15.55
Test	<i>t</i> = -1.91, <i>p</i> = .058	<i>t</i> = -3.49, <i>p</i> = .001	<i>t</i> = 3.39, <i>p</i> = .001
Socioeconomic status			
Income is less than expenses	52.36 ± 10.96	11.69 ± 4.45	38.33 ± 11.64
Income equals expenses	42.30 ± 12.79	6.85 ± 5.08	52.30 ± 16.98
Test	<i>t</i> = -4.39, <i>p</i> = .001	<i>t</i> = 4.27, <i>p</i> = .001	<i>t</i> = -4.39, <i>p</i> = .001

While there was no significant relationship between mothers' education level, family type and UCLA LS score, there was a statistically significant correlation between mothers' employment status, social security coverage, socioeconomic status and UCLA LS score ($p < .05$; Tab. 3).

A similar trend was observed when considering the BHS mean score and the mothers features (Tab. 3). In fact, the BHS mean score was higher in illiterate mothers (12.09 ± 5.25), followed by mothers with primary-secondary school education (10.96 ± 4.48) and by mothers with high school or higher education (8.52 ± 4.82). Unemployed mothers felt more hopeless (11.09 ± 4.76) in coping with disabled children than employed mothers (2.50)

± 1.00) and the same was observed in mothers with an extended family type (12.68 ± 4.48) vs nuclear family type (10.36 ± 4.95), mothers without social security (12.20 ± 4.34) vs mothers with social security (9.00 ± 5.09) and mothers whose income was less than their expenses (11.69 ± 4.45) as opposed to mothers whose income was equals to their expenses (6.85 ± 5.08). Interestingly, with the only exception of the family type variable, a statistically significant correlation was found between the mothers' level of education, employment status, social security coverage, socioeconomic status and mean BHS score ($p < .05$; Tab. 3).

As expected, an opposite trend was observed when considering the MSPSS mean score and the mothers features (Tab. 3). In this case, in fact, the higher was the score, the higher was the mothers' perceived social support. Thus, mothers with a high school or a higher education perceived a higher social security (41.43 ± 15.06) than mothers with a primary-secondary school education (40.72 ± 13.26) but surprisingly illiterate mothers reached an MSPSS mean score (41.03 ± 14.31) that was comparable to highly educated mothers. Working mothers also perceived a higher social support (59.50 ± 17.40) than non-working mothers (40.24 ± 13.29) and the same trend was observed in mothers with a nuclear family type (41.97 ± 14.20) vs extended family type (36.36 ± 11.37), in mothers with social security (45.85 ± 15.05) vs mothers without social security (37.08 ± 15.55) and in mothers whose income was equals to their expenses (52.30 ± 16.98) as opposed to mothers whose income was less than their expenses (38.33 ± 11.64). While no statistically significant correlation emerged between mothers' education level, family type and MSPSS mean score ($p > .05$), there was a statistically significant correlation between the mothers' employment status, social security coverage, socioeconomic status and MSPSS mean score ($p < .05$; refer to Tab. 3 for more details).

While there was a positive and statistically significant correlation between the UCLA LS mean score and the BHS mean score ($p < .05$), a negative and statistically significant correlation was observed between the UCLA LS mean score and the MSPSS mean score ($p < .05$; see Tab. 4 for more details). A positive and statistically significant relationship between the BHS scale mean score and the UCLA LS mean score ($p < .05$) was again observed, as opposed to a negative and statistically significant correlation with the MSPSS mean score ($p < .005$; Tab. 4).

Although not included in the table, there was no significant relationship between the child's level of intellectual disability and the mothers' UCLA-LS, BHS and MSPSS mean scores ($p > .05$).

Table 4 – *The relationship between mothers' Total UCLA LS, BHS and MSPSS mean scores*

Features		UCLA LS	BHS	MSPSS
UCLA LS	<i>r</i>	1	.602**	-.633**
	<i>p</i>		< .001	< .001
BHS	<i>r</i>	.602**	1	-.661**
	<i>p</i>	< .001		< .001
MSPSS	<i>r</i>	-.633**	-.661**	1
	<i>p</i>	< .001	< .000	

4. Discussion

This study was conducted in a region of Turkey where services and opportunities for disabled individuals are limited, and social support resources are inadequate. We thus considered crucial to determine the levels of hopelessness and loneliness among mothers of disabled children and to associate them with social support to highlight the problems of a disadvantaged group. It should be underlined that, although interesting, the study's findings are limited due to the small sample size that prevents generalizability.

The need for care and the dependency on a caregiver of disabled individuals can be a challenging situation for parents to come to terms with and it can create disparities in family roles and responsibilities. The family may face difficulties related to the child's care needs, health issues, and education. It is unavoidable that mothers will experience more challenges as they usually take on the primary caregiving role for the disabled child.

One of the most significant psychosocial issues faced by mothers with disabled children is loneliness. Caring for a disabled child can result in a decrease in social support and can contribute to feelings of isolation and depression. In this study, we found that the level of loneliness expressed by the mothers (UCLA-LS $M \pm SD = 50.56 \pm 11.94$) was considerably higher than that reported in previous findings. For example, Gosztyła and Prokopiak (2017) reported the mean loneliness score to be 28.11 ± 8.95 . Ergün and Ertem (2012) reported that 19.2% of mothers experienced loneliness, while Şen and Yurtsever (2007) reported that only 8.7% of mothers experienced loneliness in their study. Yaşar and Bıçakçı (2019) found that as the severity of intellectual disability in the child increased, the level of loneliness among mothers also increased. All the findings, taken

together, indicate that loneliness is a significant psychosocial problem experienced by mothers of disabled children.

While every parent hopes for a healthy child, having a disabled child can have negative effects on the entire family, expressed by emotions, thoughts, and behaviors. These effects are particularly felt by mothers who are the primary caregivers of the child, especially when fathers have negative attitudes towards the disabled child. This can cause mothers to experience stress, depression, and hopelessness, which can play a key role in the development of depression. In this study, the level of hopelessness among the mothers was found to be moderate. In another study, Balcı and colleagues (2019) reported that 91.9% of mothers expressed anxiety of the future and 52.5% felt hopeless. Ceylan and Aral (2007) reported that the level of hopelessness among mothers was high, while Ergün and Ertem (2012) found that 39.9% of mothers were worried about the future. In our study, we observed that the level of hopelessness decreased as the education level, employment status, economic status, and social security support increased. In another study, it was reported that the level of hopelessness among mothers who graduated from primary and secondary school was higher than that of mothers who had a university education (Zembat & Yıldız, 2010). This suggests that factors related to the level of education and economic status have an impact on the level of hopelessness experienced by mothers.

Sharing one's feelings and thoughts and receiving support can help individuals fulfill their social roles and adapt to changes in their lives. Balcı and colleagues reported that 48.8% of mothers with disabled children could not find someone to help them with childcare and needed support from those around them (Balcı *et al.*, 2019). Social support is considered a valuable resource for people to assist one another. Social support networks have been shown to be effective in promoting the psychological well-being of individuals facing stressful situations. It is crucial for mothers of disabled children to adjust to their new roles and cope with psychosocial challenges. In this study, the mothers' total MSPSS mean score was 40.97 ± 13.86 , indicating that they received social support primarily from their family, significant other sources, and friends. A previous study by Sridevi (2014) found that the perceived social support score by parents was 47.70 ± 6.41 , indicating that in this case the mothers of disabled children perceived a higher social support. In the current study, mothers who worked, had social security, and considered their socioeconomic status to be higher reported a higher average perceived social support score. Deveci and Ahmetoğlu

(2018) found that the perception of a stable economic situation and of social security was positively correlated with the perceived social support score. Additionally, individuals with a high level of economic status and social security reported higher perceived social support scores. Likewise, Yaşar and colleagues (Yaşar, Vural-Batik, & Özdemir, 2020) reported that higher levels of education were associated with lower levels of anxiety among mothers of disabled children, but their social support levels were low. In another study, Devenci and Ahmetoğlu (2018) found a significant correlation between social support and perceived economic status, with higher perceived socio-economic levels corresponding to higher perceived social support scores. Taken together, the findings of the current study and of previous studies suggest that working status, perceived economic status, and social security are related to receiving social support. In terms of social support, the socio-cultural construction of the perception of disability in society is important. In the study of Kirshbaum and Olkin (2002), the authors stated that the social construction process and cultural dimension of disability should not be underestimated.

Studies on mothers of disabled children recommend providing professional support to families experiencing psychosocial problems (Scharer, Colon, Moneyham, Hussey, Tavakoli, & Shugart, 2009; Devenci & Ahmetoğlu, 2018; Akram, Batool, & Bibi, 2019). Such support was shown to be effective in reducing difficulties experienced by families (Sridevi, 2014; Gilson, Davis, Johnson, Gains, Reddihough, & Williams, 2018; Telci *et al.*, 2018). Since mothers are usually the primary caregiver for the child, it is essential to strengthen and support them. In our study, a positive correlation was found between the mean scores of loneliness and hopelessness, while a negative correlation was observed between the mean scores of loneliness and hopelessness and the level of perceived social support. Gosztyła and Prokopiak (2017) found a correlation between the social support levels and loneliness levels of mothers and they reported that the perceived social support negatively affected the level of loneliness. Likewise, Yaşar and Bıçakçı (2019) reported that individuals with high levels of loneliness had poor social support and mothers of disabled children required social support. Raising a child with a disability can lead to problems, such as loneliness, isolation, and decreased social support (Gosztyła & Prokopiak, 2017). In line with this, Akram and colleagues (2019) found that social support reduced the caregiving burden of mothers and the risk to commit suicide. Gilson and collaborators reported that about 48% of mothers of disabled children had psychological problems, such as

depression, anxiety, and suicidal tendencies, and needed psychological support (Gilson *et al.*, 2018). Overall, the present study and previous findings suggest that loneliness, depression, negative thoughts concerning the future and hopelessness (which is a cause of depression) are all related to social support.

5. Conclusions

According to research, mothers with disabled children often experience psychosocial difficulties, such as loneliness and hopelessness. Social support is necessary to help these mothers strengthen their psychosocial well-being. The well-being of mothers is important not only for their personal ability to cope with difficulties, but also to provide optimal care for their child. When support is insufficient, it can negatively affect the care of the disabled child. Therefore, it is important to organize awareness-raising activities for all employees, especially health professionals, who work with disabled individuals to support the psychosocial well-being of mothers with disabled children.

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