

Running Head: PSYCHOLOGICAL HEALTH OF PARENTS

Psychological Health of Parents of Children with Autism Spectrum Disorders

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Abstract

There is clear evidence that parents of children with disabilities face challenges that can lead to negative outcomes, including heightened stress and depression. Less well understood is how stress levels, coping strategies, and psychological well-being may differ among parents dealing with different types of disabilities. The current study addressed this issue by comparing the outcomes of parents of children diagnosed with three different nervous system disabilities: Down syndrome, Fragile-X syndrome, and Autism Spectrum Disorder. Parents of typically-developing children were also assessed. Participants (N = 114) were notified of this study via on-line support groups and completed surveys on-line. Unlike the findings of recent studies, parents of children with Autism Spectrum Disorder did not report higher levels of stress and depression compared to all other groups. Parents of children with Down syndrome were found to have the lowest levels of stress and depression compared to all other groups. Parents of typically developing children used significantly less problem-focused coping strategies compared to all disabilities. These findings indicate that there are no differences in the levels of depression and stress on parents of children with Autism Spectrum Disorder and coping strategies are similar for parents whose children have the studied nervous system disabilities.

Psychological Health of Parents of Children with Autism Spectrum Disorders

The number of children diagnosed with Autism Spectrum Disorder (ASD) in the United States is rising. In 1943, an estimated 3 children out of 10,000 were diagnosed with Autism. In the late 1990's, Autism prevalence rates reached 60 out of every 10,000 births with the rates increasing when including all disorders of the Autism Spectrum (Wing & Potter, 2002). The disorders that from the Autism Spectrum include Rett's Disorder, Childhood Disintegrative Disorder, Asperger's Disorder, and Pervasive Developmental Disorders-not otherwise specified. Children diagnosed with any ASD have symptoms that vary from mild to severe, and all experience some degree of impairment in their communication skills, social interactions, and behaviors. For example, some Autistic children are largely non-verbal, some have emotional tantrums, and some engage in repetitive behaviors (e.g. hand flapping) (National Institute of Child Health and Human Development, 2008).

Not surprisingly, parents of children with Autism often score above the mean on tests of aggravation and stress when compared to children without any developmental disability and, according to some research, even when compared to parents with children with other developmental disabilities (Schieve, 2007). The purpose of the present study is to examine the psychological health of parents of children with Autism Spectrum Disorder, especially as compared to that of parents of children with two other disabilities: Down syndrome, and Fragile-X syndrome. Specifically, these three groups will be compared in terms of their levels of depression, stress, and coping strategies.

These three disabilities were selected because they qualify as nervous system disabilities. A nervous system disability is one which results from an impairment in the brain, spinal cord, or nervous system which then causes varying difficulties in learning and intelligence (National

Institute of Child Health and Human Development, 2008). In Down syndrome, this impairment leads to mild to moderate mental retardation, delayed language development, and slow motor development. In Fragile-X syndrome the impairments lead to mental retardation, hyperactivity, short attention span, and perseverative speech.

Psychological Health among Parents of Children with Developmental Disabilities

Stressors come along with parenting any child. However, research has shown that when a child has developmental disabilities, including Autism, parents are often at a higher risk for many negative psychological outcomes (Schieve, 2007). In dealing with the intellectual, linguistic, and behavioral issues that may characterize their child's disability, parents of children with developmental needs often must pay more medical bills, are less able to focus on the lives of their other children, and may have to spend more time at home with the child, reducing time for themselves (Stoneman, 2007, p. 1014). Certainly, many of these stressors are common to parents of all children with developmental disabilities, but there are reasons to believe that different disabilities will be associated with different stressors and with different levels of stress.

Based on previous research, if there is one developmental disability for parents that can be called at all "advantageous", that disorder is Down syndrome. Previous research by Z. Stoneman (2007) claims that compared to other developmental disabilities there is a "Down syndrome advantage" for parents. Parents of children with Down syndrome have been compared to parents of children of other disorders, and the parents of the Down syndrome children have lower levels of depression, higher levels of self-reported warm parenting, and higher levels of maternal warmth observed by others (Stoneman, 2007, p. 1014). Other research shows similar results as parents of children with Down syndrome experience less stress and more rewards compared to parents of children with other disabilities (Hodapp, Ly, Fidler, & Ricci, 2001). In

fact, Hodapp et al. (2001) shares that parents of children with Down syndrome may have equal rewards when compared to parents of “typical” children, as defined by children who have had no clinically diagnosed disabilities.

Less research has been done to examine the outcomes of parents of children diagnosed with Fragile-X syndrome and the work that has been done has yielded somewhat mixed results. For example, research by Lewis et al. (2006) found that there is a low effect of stress on parents, compared to parents of some other developmental disabilities. At the same time, these mothers of Fragile-X children are more pessimistic and report more family conflict as well (Lewis et al., 2006). Additionally, more challenges are presented for parents of these children compared to those of Down syndrome (Lewis et al., 2006).

Further complicating comparisons among groups is that potentially confounding variables, like level of parental education, have not always been taken into account. The importance of controlling for these potential confounds was demonstrated in a recent study by Stoneman (2007) who found that once analyses controlled for parental income, parents of children with Down syndrome showed no advantage relative to parents of children with other disabilities considered together. Since older parents often are the ones that have Down syndrome children, such parents commonly are already financially stable. Interestingly, after removing the variable of income, there is still a Down syndrome advantage when compared to parents with children with Autism. Stoneman (2007) claims that these findings may, in fact, not be supportive of a Down syndrome advantage, but rather an “autism disadvantage” (p.1014).

Indeed, other research shows signs of an “autism disadvantage” due to added social and behavioral problems faced by parents of children with Autism (Schieve, 2007; Stoneman, 2007). Though in some respects, the intellectual disabilities of children with Autism are less, the social

and behavioral problems of children with Autism are usually higher when compared to typically developing children and others with developmental disabilities. Parents of children with Autism Spectrum Disorders experience higher levels of parenting stress when compared to parents of typically developing children (Shieve, 2007). This may be a result of several varying reasons, including the sleep patterns of children with ASD are more problematic when compared to the patterns of typical children, thus, the sleep pattern of the ASD parents are worse (Lopez-Wagner, Hoffman, Sweeney, Hodge, & Gilliam, 2008). Additionally, parents of children with Autism experience more felt and enacted stigmas, as compared to other parents whose children have disabilities (Gray, 2002). It has also been found that ASD parents also experience higher levels of aggravation compared to parents of children with other disabilities, other healthcare needs, or no healthcare needs at all (Schieve, 2007).

Overview

In the current study, we explore the possibility of and “autism disadvantage” by comparing the stress levels, depression levels, and coping strategies of parents of children with Autism with those of parents of children with the two other nervous system disabilities and parents of typically developing children. We expect that parents of Autistic children will report higher levels of stress, higher levels of depression, and less effective coping strategies when compared to Down syndrome, Fragile-X syndrome, and typically developing children.

To examine parent’s coping strategies, we draw upon prior research that has distinguished two general coping strategies: problem-focused and emotion-focused. When parents engage in problem-focused coping they tend to seek support from others (e.g. family members or medical professionals) in an attempt to find a solution to the problems they are experiencing. In contrast, when parents engage in emotion-focused coping, they tend to focus on

ways of managing their emotions rather than solving the problem at hand. For example, parents may try to thinking differently about their situation, ignore the situation, or even blame themselves for what has happened. Although evidence is somewhat mixed, most research seems to suggest that problem-focused coping leads to better outcomes than emotion-focused coping. For example, Judge (1998) found that parents who use problem-focused coping to deal with disability-related problems felt less distress and depression compared to those who used emotion-focused coping strategies. Consistent with these findings, we anticipate that parents of children with ASD will use less problem-focused coping and significantly more emotions focused coping than parents in the other groups, causing increased depressive moods and stress.

Method

Participants

114 participants volunteered to participate in our study (12 % men, 88 % women). The participants' ages ranged between 19 and 64 with a mean of 38 years. Participants were parents to children with Nervous System Disabilities including Down syndrome ($N = 31$), Autism Spectrum Disorders ($N = 24$), and Fragile-X ($N = 31$). Some parent participants with children who have no diagnosed disabilities were included ($N = 28$).

Measures

Our study consisted of a questionnaire, which was made of demographic questions, and close ended questions. For a stress scale we used the Parental Stress Scale (PSS) developed by Berry and Jones (1995). We used the *Center for Epidemiologic Studies Depression Scale* (CES-D) as our depression scale (Appendix A). Additionally, we are using the Abbreviated Version of the Ways of Coping Inventory (WoC-Abbr) (Appendix B). The WoC-Abbr is a 44-item

abbreviated version (Parkes, 1984) of the Ways of Coping Scale (Folkman & Lazarus, 1980). For our purposes and for practicality, we abbreviated the scales to include 55 items in total.

The Parental Stress Scale (PSS) was developed as a considerably shorter alternative to the Parental Stress Index and proves to be a very reliable measure (Berry & Jones, 1995). There are 18-items on the scale (e.g., Caring for my child(ren) sometimes takes more time and energy than I have to give). The scale is on a 5-point response format and the following numbers correspond to certain answers: 1 = 'strongly disagree'; 2 = 'disagree'; 3 = 'neutral'; 4 = 'agree'; and 5 = 'strongly agree.' Participants' responses were averaged across the 18 items so that higher scores indicate higher levels of stress. Certain items were reversed in scoring.

The Center for Epidemiologic Studies Depression Scale (CES-D) measures the number of depressive symptoms that respondents have experienced in the last week and how often the respondent has experienced these symptoms (Schroevers, Sanderman, van Sonderen, & Ranchor, 2000). There are 12-items in the scale (e.g., I felt that I was just as good as other people)The following numbers correspond to certain answers: 0 = 'rarely or none of the time'; 1 = 'some or a little of the time' (1-2 days per week); 2 = 'occasionally or a moderate amount of the time' (3-4 days per week); 3 = 'most or all of the time' (5-7 days per week). Participants' responses were averaged across the 20 items so that higher scores indicate more depressive symptoms.

The Abbreviated Version of the Ways of Coping Inventory (WoC-Abbr) was used to determine the degree to which parents used problem-focused versus emotion-focused coping strategies in raising their child (Parkes, 1984). Parents were presented with 25 coping strategies, 7 of which

were problem-focused and the remainder of which were emotion-focused. The answers were coded with the numbers 1 (if the strategy was used) and 0 (if the strategy was not used in raising the child). Responses were averaged separately for the two sub-scales so that higher scores indicated more problem-focused or more emotion-focused coping.

Demographic questions were included so that we could measure the income levels of the families, the diagnosis of their children, the sex and age of the child, as well as other demographic items.

Design and Procedure

Participants read an online Informed Consent form, which stated that the study consisted of a demographic questionnaire, as well as another questionnaire. If the participants gave their consent to participate in our study, they then used the link provided via Hanover College's psychology department website to access the questionnaires. After answering the questions and submitting their responses, participants were directed to an online debriefing form and were thanked for their participation in this study.

Participants were recruited through a series of internet sites and newsgroups. All the newsgroups and internet sites utilized cannot be known by the researchers because all participants were asked to put the online survey on other groups that they were members of and to share the survey with personal friends and family that could be potential participants. However, it is believed that the following sites recruited the most participants. For parents of children with Down syndrome, the researchers used DownSyn Forum. For parents of children with Fragile-X syndrome, the researchers used Fragile_X_Michigan and Fragile X Yahoo Group. For parents of children with Autism Spectrum Disorder, the researchers used ds-autism.

Other sites and support groups used included

Parents_of_special_needs_kids_DE_MD_PA@yahoo.com and Timetotalk.

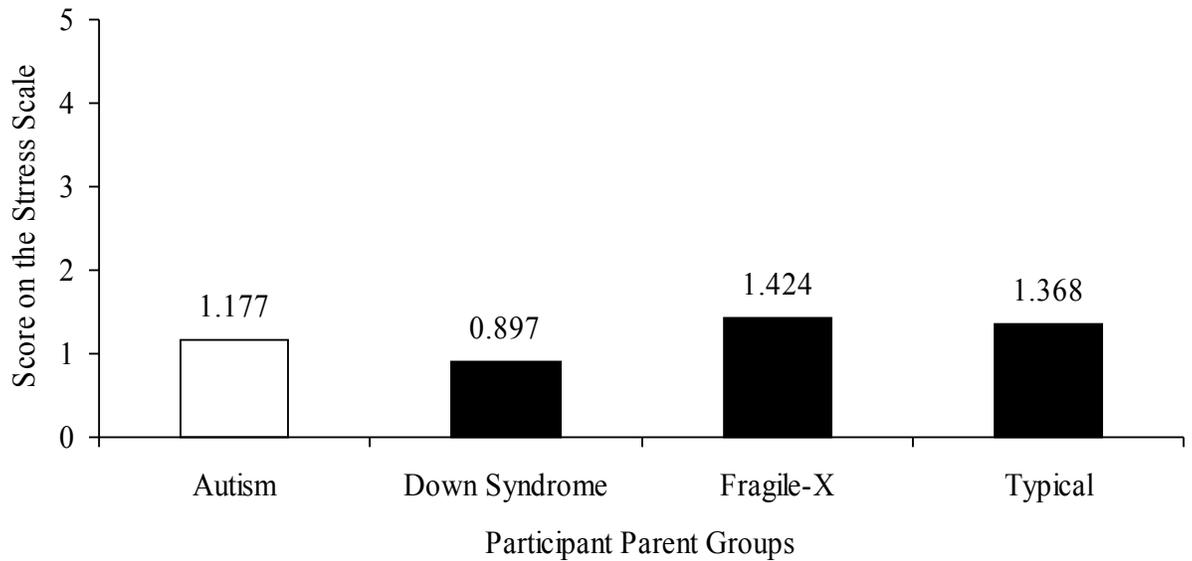
Results

The researchers tested the reliability of the three surveys that were used for the study. All three of the scales were reliable. The Stress Scale had a Cronbach's Alpha of .869, the depression Scale had a Cronbach's Alpha of .849, and the. The researchers measured the reliability of the Coping Scale by separating the questionnaire into two sections; the Emotion Focused Coping scale had a Cronbach's Alpha of .755, whereas the Problem Focused Coping scale had a Cronbach's Alpha of .794.

Differences among groups in stress levels, depression levels, and coping strategies were assessed using univariate analyses of variance (ANOVA). Analyses of covariance (ANCOVA) were run to control for age and education level. However, the results did not differ from those obtained without controlling for these variables. The results of the ANOVA analyses are presented here.

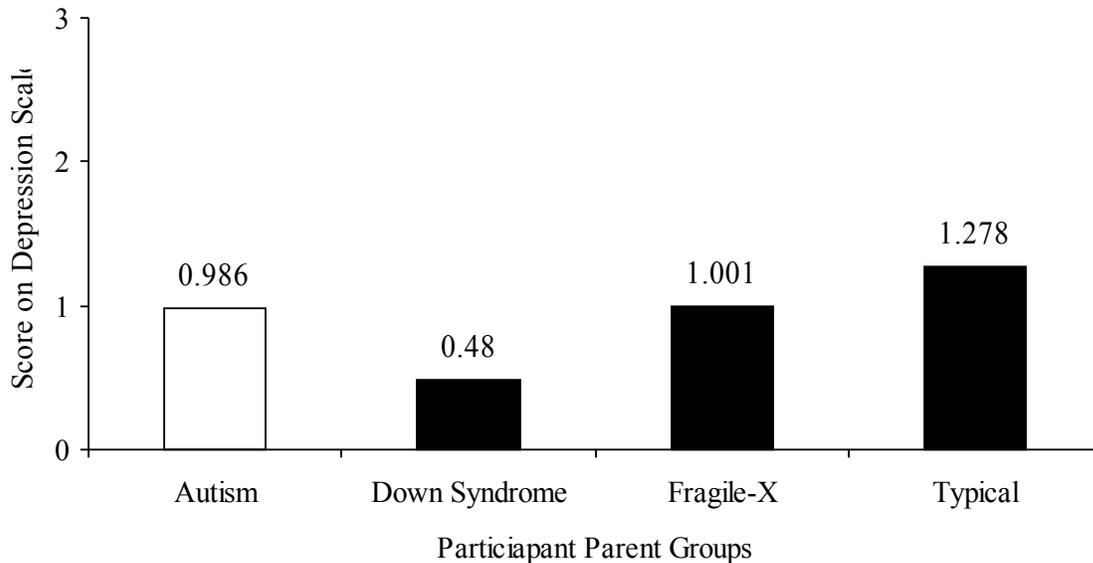
There was a significant difference in the stress levels of the participating parents $F(3, 109) = 4.299, p = 0.007$. The post-hoc test showed that the stress levels for parents of children with Down syndrome ($M = .897$) was significantly lower than stress levels of parents of children with Fragile-X ($M = 1.424$), ($p = .001$) and "typically-developing" ($M = 1.368$) children ($p = .006$), and marginally lower than stress levels of parents of children with ASD ($M = 1.177$) ($p = .106$) (see Figure 1).

Figure 1. Stress levels across participant groups.



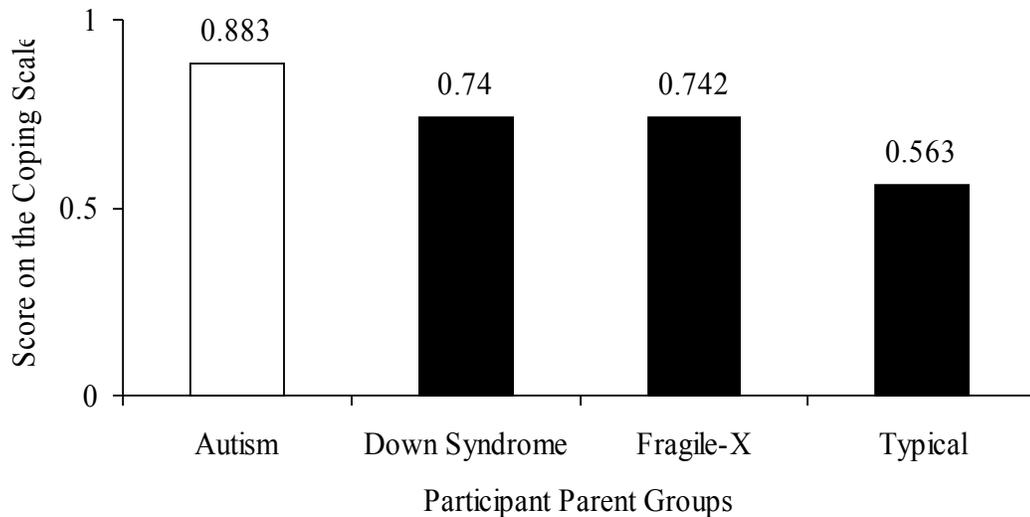
Analyses revealed a significant difference in the depression levels of the participating parents $F(3, 110) = 10.366, p < 0.001$. Post-hoc tests showed that the depression levels for parents of children with Down syndrome ($M = .501$) were significantly lower ($p < 0.001$) than depression levels for parents of children with Autism ($M = 1.038$), Fragile-X ($M = 1.013$), and “typically-developing” children ($M = 1.228$) (see Figure 2).

Figure 2. Depression levels across participant groups.



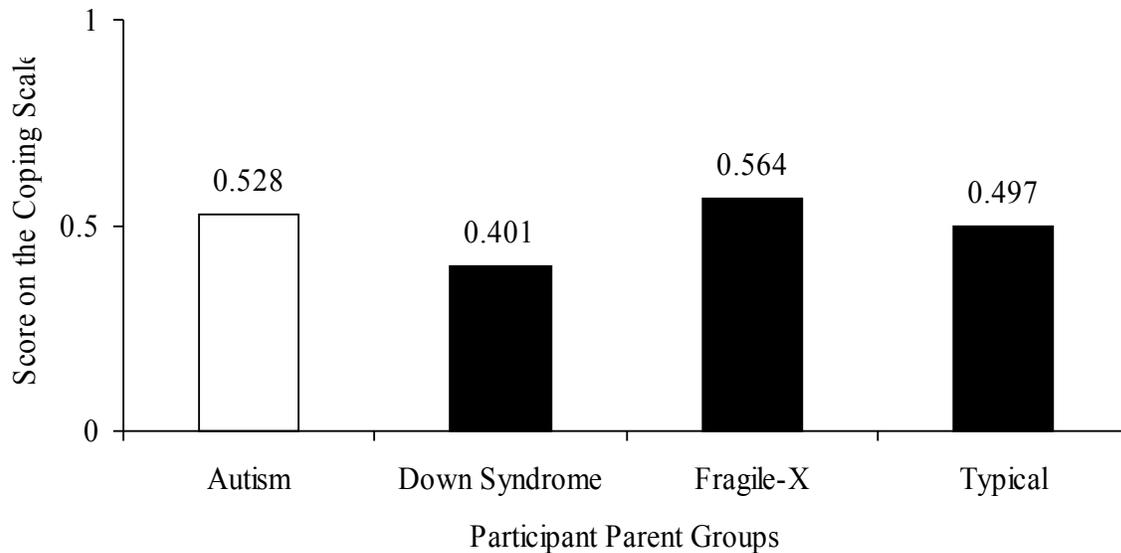
There was a significant difference in the amount of problem focused solving used by the different groups of participants $F(3, 108) = 4.406, p = 0.006$. The post-hoc test showed that the parents of children with “typically-developing” children used problem focused coping significantly less ($M = .563$) than parents of children with Autism ($M = .883$) ($p < .001$), Down syndrome ($M = .740$) ($p = .037$), and Fragile-X ($M = .742$) ($p = .034$) (see Figure 3). Moreover, parents of autistic children were marginally more likely to use problem-focused coping than parents of children with Down syndrome ($p = .101$) and parents of children with Fragile-X ($p = .103$).

Figure 3. Problem focused coping across participant groups.



There was a significant difference in the amount of emotion focused coping used by the different group of participants $F(3, 108) = .147, p = 0.029$. The post-hoc test showed that the parents of children with Down syndrome ($M = .401$) used emotion focused coping significantly less than parents of children with Autism ($M = .528$) ($p = .034$), and Fragile-X ($M = .564$) ($p = .004$) (see Figure 4).

Figure 4. Emotion focused coping across participant groups.



Discussion

This study was designed to see whether there were differences in the psychological health of parents of children with Autism, Down syndrome, Fragile-X, and children that have a typical development. The researchers expected to find that the parents of children with Autism would experience higher levels of stress, and depression, and would use fewer or poorer coping strategies. The hypothesis was partially supported: The parents of children with ASD had significantly higher levels of depression, marginally higher levels of stress, and engaged in significantly more emotion-focused coping strategies than parents of children with Down syndrome. Importantly, the difference was not significant when the comparison was with the parents of children with Fragile-X, or typically developing children. These findings suggests that, what we are seeing may not be a global “autism disadvantage”, but, instead, a disadvantage relative to parents of children with Down syndrome (a phenomenon noted in prior work and

termed the “Down syndrome Advantage”). One reason why we may not have found a global autism disadvantage in our study is that parents of children with ASD in our sample practiced significantly more problem-focused coping than parents of typically developing children and marginally more problem-focused coping than parents of both Down syndrome and Fragile-X syndrome. This type of coping may benefited these parents, leading to somewhat lower stress and depression levels than we might have otherwise seen. Indeed, previous research problem focused coping in parents of children with ASD leads to higher levels of maternal well-being, regardless of symptomatology (Gray, 2006; Smith et al., 2008). It will be important for future research to determine whether this relatively high level of problem-focused coping is typical of most parents of children with autism, or whether it is simply typical of the group we sampled: parents who have sought support on- line. There is reason to suspect that, although problem-focused coping may be higher among parents who seek out news-groups, social support seeking may be increasing among many parents of autistic children as the stigma of the disability is waning. The researchers believe that an increased amount of Autism awareness campaigns, spotlight articles in major magazines, fundraisers for ASD, and many other social support networks, have provided parents of these children to have more resources available for their coping than ever before. These events could have drastically increased the ASD parents’ use of problem-focused coping in the last few years.

An interesting finding of this research is one that supports previous research on the Down syndrome advantage; even when controlling for all socioeconomic markers, a significant advantage characterized by less stress and depression among parents of children with Down syndrome when compared to all other research populations. Moreover, the researchers also found a Down syndrome advantage when compared to the parents of typically developing children. It is

believed by the researchers, however, that the children may not be so “typical.” Not only are they parents on various parent support internet sites, the researchers never asked parents their situation with children. Other variables could have played a part in parent psychological health.

Future Research

Future research in this area should use more socioeconomic markers for research comparison of groups. Where the current study looked at educational level as the main socioeconomic marker, it would certainly be interesting to look at income levels. Moreover, there should be a more in depth analysis of type of coping skills and strategies. There are many types of coping strategies and the current study focused on two general categories of coping. Also, the researchers should get more confirmation that their control group is actually made up of parents of typically developing children. Since the current group of parents with typically developing children simply shared that their children do not have any diagnosed disability, the researchers suppose that they still may not be typical. The parents are still active in these support newsgroups online, so they possibly need help raising their children and the children are not so typical.

Appendices

A. *Center for Epidemiologic Studies Depression Scale (CES-D)*

	<u>0</u>	<u>1</u>	<u>2</u>	<u>3</u>
1. I was bothered by things that usually don't bother me	–	–	–	–
2. I did not feel like eating, my appetite was poor	–	–	–	–
3. I felt that I could not shake off the blues even with the help from my family or friends	–	–	–	–
4. I felt that I was just as good as other people	–	–	–	–
5. I had trouble keeping my mind on what I was doing	–	–	–	–
6. I felt depressed	–	–	–	–
7. I felt that everything I did was an effort	–	–	–	–
8. I felt hopeful about the future	–	–	–	–
9. I thought my life had been a failure	–	–	–	–
10. I felt tearful	–	–	–	–
11. My sleep was restless	–	–	–	–
12. I was happy	–	–	–	–
13. I talked less than usual	–	–	–	–
14. I felt lonely	–	–	–	–
15. People were unfriendly	–	–	–	–
16. I enjoyed life	–	–	–	–
17. I had crying spells	–	–	–	–
18. I felt sad	–	–	–	–
19. I felt people disliked me	–	–	–	–

20. I could not get going - - - -

B. *The Ways of Coping Inventory (WoC-Abbr)*

	<u>0</u>	<u>1</u>
1. Talked to someone who could do something concrete about the problem.	-	-
2. Got professional help and did what they recommended.	-	-
3. Asked someone you respected for advice and followed it.	-	-
4. Made a plan of action and followed it.	-	-
5. Just concentrated on what you had to do next.	-	-
6. Stood your ground and fought for what you wanted.	-	-
7. Concentrated on something good that could come out of the whole thing.	-	-
8. Changed something so things would turn out all right.	-	-
9. You knew what had to be done, so you doubled your efforts and tried harder to make things work.	-	-
10. Just took things one step at a time.	-	-
11. $\bar{\bar{}}$ Wished you were a stronger person—more optimistic and forceful.	-	-
12. $\bar{\bar{}}$ Wished that the situation would go away, or be over with.	-	-
13. $\bar{\bar{}}$ Wished that you could change what had happened.	-	-
14. $\bar{\bar{}}$ Tried to make yourself feel better by eating, drinking, smoking, taking medication, etc.	-	-
15. Hoped a miracle would happen.	-	-
16. $\bar{\bar{}}$ Felt bad that you couldn't avoid the problem.	-	-
17. $\bar{\bar{}}$ Daydreamed or imagined a better time/place than the one you were in.	-	-
18. $\bar{\bar{}}$ Wished that you could change the way you felt.	-	-
19. $\bar{\bar{}}$ Had fantasies or wished about how things might turn out.	-	-
20. $\bar{\bar{}}$ Blamed yourself.	-	-
21. $\bar{\bar{}}$ Took it out on other people.	-	-
22. $\bar{\bar{}}$ Tried to forget the whole thing.	-	-
-		

- 23. Didn't let it get to you; refused to think too much about it. —
- 24. $\bar{\bar{}}$ Made light of the situation; didn't get too serious about it. —
- 25. $\bar{\bar{}}$ Went on as if nothing had happened. —
- 26. $\bar{\bar{}}$ Accepted the next best thing to what you wanted. —
—
- 27. You felt that time would make a difference, the only thing to do was to wait. — —
- 28. Tried not to act too hastily or follow your first hunch. — —
- 29. $\bar{\bar{}}$ Went along with fate; sometimes you just have bad luck. —
- 30. $\bar{\bar{}}$ Talked to someone to find out more about the situation. —
- 31. $\bar{\bar{}}$ Let your feelings out somehow. —
- 32. $\bar{\bar{}}$ Talked to someone about how you were feeling. —
- 33. $\bar{\bar{}}$ You went over the problem again and again in your mind to try to understand it. — —
- 34. Accepted sympathy and understanding from someone. — —
- 35. $\bar{\bar{}}$ Made a promise to yourself that things would be different next time. —
- 36. $\bar{\bar{}}$ Tried to make up to someone for the bad thing that happened. —
- 37. $\bar{\bar{}}$ Told yourself things that helped you feel better. —
- 38. $\bar{\bar{}}$ Waited to see what would happen. —
- 39. $\bar{\bar{}}$ Thought about fantastic or unreal things that made you feel better. —
- 40. $\bar{\bar{}}$ Tried not to burn your bridges behind you. —
- 41. $\bar{\bar{}}$ Rediscovered what is important in life. —
- 42. $\bar{\bar{}}$ Came up with a couple of different solutions to the problem. —
- 43. $\bar{\bar{}}$ Criticized or lectured yourself. —
- 44. $\bar{\bar{}}$ Turned to work or substitute activity to take your mind off things. —
—

11.		Having children has				
been a financial burden.	1		2	3	4	5
12.		It is difficult to				
balance different responsibilities because of my child(ren).	1		2	3	4	5
13.		The behavior of my				
child(ren) is often embarrassing or stressful to me.	1		2	3	4	5
14.		If I had it to do over				
again, I might decide not to have children.	1		2	3	4	5
15.		I feel overwhelmed				
by the responsibility of being a parent.	1		2	3	4	5
16.		Having children has				
meant having too few choices and too little control over my life.	1		2	3	4	5
17.		*I am satisfied as a				
parent.	1		2	3	4	5
18.		*I find my child(ren)				
enjoyable.	1		2	3	4	5

D. Open-Ended Questionnaire

1. What is the most difficult situation you have found yourself concerning your child? [???](#)
2. When you first found out the diagnosis of your child, what were your feelings?
3. Please explain the coping strategies that you use the most in trying to control stress concerning your family.
4. When you look back at your life, what are the most positive and most negative times?

5. If you had to be a parent for your child all over again, what would you change and what would you keep the same.

6. Comments and anything else you would like to share:

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