

# Social support in parents of children with neurodevelopmental disorders

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The aim of the present study was to compare the social support in parents of children with neurodevelopmental disorders. The sample consisted of 166 parents of children with neurodevelopmental disorders in Isfahan, Iran. Medical Outcomes Study Social Support Survey (MOS-SSS, Sherbourne and Stewart 1991) was used for measuring the availability of social support. The collected data were analyzed using two-way analysis of variance and multivariate analysis of variance. The results showed that there was no significant difference in social support scores between parents of children with neurodevelopmental disorders based on the type of child disorder and the gender of the parents ( $p > 0.05$ ). The results also showed that there was no significant difference in the subscale of emotional/informational support, tangible support, and affectionate support between parents of children with neurodevelopmental disorders ( $p > 0.05$ ) but in the one subscale (i.e. social interaction) parents of children with intellectual disability was significantly higher than parents of children with autism spectrum disorder and parents of children with attention deficit hyperactivity disorder. Moreover, The results showed that there was no significant difference in subscales of social support between parents of children with neurodevelopmental disorders based on the gender of the parents ( $p > 0.05$ ). Therefore, according to the research findings, the design and implementation of support and educational programs for parents of children with neurodevelopmental disorders, especially in parents of children with ASD and ADHD, and to increase social interactions are essential and should be a priority in the programs of organizations providing psychological services.

**Keywords:** social support, parents, children, neurodevelopmental disorders

## Introduction

Neurodevelopmental disorders (NDDs) are defined as a group of disorders caused by changes in early brain development, resulting in behavioral and cognitive alterations in sensory and motor systems, speech, and language (Blackmer and Feinstein 2016). Intellectual Disability (ID), Autism Spectrum Disorder (ASD), and Attention Deficit Hyperactivity Disorder (ADHD), are the three most common types of NDDs (American Psychiatric Association 2013). ID is a disability characterized by significant limitations in cognitive functioning, together with major difficulties acquiring adaptive behaviors. This disability originates before the age of 18 (Schalock *et al.* 2010). ASD refers to a continuous disturbance in verbal and nonverbal communications and social interaction, limited and repetitive behavior from an early age, and adversely affects a child's performance in everyday life (American Psychological Association 2013). Attention Deficit Hyperactivity Disorder (ADHD) is a disorder recognized by an ongoing pattern of inattention, hyperactivity, and impulsivity that interferes with functioning or development (APA 2013).

The birth of a child with NDDs is often accompanied by low levels of quality of life (Giallo *et al.* 2013), decreased life satisfaction and optimism for the future (Ingersoll and Hambrick 2011), and increased anxiety, depression and isolation (Lu *et al.* 2018) for parents. For this reason, caring for children with disabilities requires more effort and resources than typically developing children, and adapting to such conditions can be tedious (Ammari *et al.* 2014). For example, Hodapp and Krasner (1994) have shown that parents of children with disabilities have higher rates of divorce. In support of this finding, Woolfson (2004) stated that a child with a disability can cause stress to parents. In this regard, studies by Chandorkar and Chakraborty (2000), Ashum and Singhal (2004), and Remine and Brown (2010) showed that the parents of these children have lower physical and psychological health and the existence of children with disabilities threatens parents health, especially mothers. In fact, the mothers of these children have more problems than the fathers and are more involved with their child's behavioral problems, and therefore experience more stress and need more support (Kessler and Ustun 2004). In general, among family members of children with disabilities, mothers are more exposed to a variety of psychological

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traumas than fathers due to the stress of their children's daily needs (Koydemir and Tosun 2009, Meadan 2010).

Social support is one of the most well-known sources for improving welfare (Goedeke *et al.* 2019). Increasing social support is associated with reducing anxiety (Lu *et al.* 2015), depression (Bromley *et al.* 2004), improving overall well-being (Goedeke *et al.* 2019), and life satisfaction (Lu *et al.* 2018). Using parental support strategies in treatment programs not only increases child and family well-being but also improves treatment outcomes (Mitchell *et al.* 2016). Family-centered psychological interventions ensure social support in the rehabilitation process by reducing anxiety and increasing emotional support and improving performance and social interactions (George *et al.* 2011). Langeland and Wahl (2009) have shown that with increasing social support, the level of health also increases. As a result, people who have the support of others tend to experience less stress in life and experience fewer psychological and physical problems than those who receive no social support from their groups (Cockerham 2006, Strazdins and Broom 2007). On the other hand, lack of social support has many negative consequences, including lack of social belonging, loneliness, and social withdrawal (Cockerham 2006, Karademas 2006).

In Iran, based on the results of Forouzan *et al.* (2013), participants did not have favorable status to perceived social support from their social network members. Savari *et al.* (2021) showed that there was a negative and significant relationship between perceived stress and the quality of life of the parents of disabled children. Moreover, there was a positive and significant relationship between social support and resilience, and the quality of life of the parents of disabled children. Moreover, Hemati Alamdarloo *et al.* (2019) concluded that perceived social support and its subscales in mothers of children with hearing impairment and mothers of children with visual impairment are significantly lower than in mothers of typically developing children.

In general, a review of empirical research shows that social support plays an important role in enhancing mental and physical health (Brouwers *et al.* 2001, Chu 2010, Dehle and Landers 2005, Gülaçtı 2010). Social support is effective in reducing stress and improving the quality of life of parents of children with NDDs (Craig *et al.* 2016) and reduces parental stress (Craig *et al.* 2016). One of the things that can increase the social support of parents is to increase the social connection of parents. Social interactions provide the context for receiving social support (Currie and Szabo 2020). Having children with NDDs can lead to further isolation of families (Currie and Szabo 2020).

The research literature on social support among parents of children with NDDs based on the types of disability is varied and contradictory. For example, Riany *et al.* (2017) showed that parents of children with ASD

have lower levels of social support than parents of children without ASD. Riany and Ihsana (2021) concluded that there is no difference between mothers of children with autism and mothers of children with ADHD in terms of social support. Seymour *et al.* (2020) showed that fathers of children with ASD had lower availability of social support than fathers of children with typical development. Flores-Buils and Andrés-Roqueta (2022) concluded that formal support variables predicted the resilience of the parents according to the type of NDD of their children.

Moreover, the research literature on social support among parents of children with NDDs based on the parents' gender is varied and contradictory. For example, Lawoko and Soares (2003) showed that mothers (both mothers of children with special needs and mothers of children with typical development) had lower availability of social support than fathers. Dyson, (1997) found that fathers and mothers of children with developmental disabilities did not differ from each other in social support. According to the findings of Sharabi and Marom-Golan (2018) fathers of children with ASD reported receiving greater formal support than mothers while mothers reported receiving greater informal support than fathers. Cavonius-Rintahaka and colleagues (2019) showed that mothers and fathers of children with NDD received social support in similar ways. Long (2009) concluded that there is no difference between fathers and mothers of children with fragile X syndrome in terms of perceived social support.

Therefore, the present study was conducted to compare social support among parents of children with NDDs (parents of children with ASD, parents of children with ID and parents of children with ADHD based on parental gender to providing appropriate information on the level of social support for parents of children with NDDs the relevant agencies and decision-making centers for implementing mental health programs and activities. For this reason, this study sought to answer the following questions:

1. Is there a significant difference between the parents of children with ASD, parents of children with ID, and parents of children with ADHD in the social support scale based on parental gender?
2. Is there a significant difference between the parents of children with ASD, parents of children with ID, and parents of children with ADHD in the social support subscales based on parental gender?

## Materials and methods

### *Population, sample, and sampling method*

The statistical population for this study included all parents of three groups of children with ND, i.e. parents of children with ASD, parents of children with ID, and parents of children with ADHD, in Esfahan, Iran. It is worth noting that each group of children with neurodevelopmental

disabilities had only one type of disability and no comorbid disorder. The sample consisted of 166 parents of children with ND, including 57 parents of children with ASD, 57 parents of children with ID, and 52 parents of children with ADHD, selected by convenience sampling method. Convenience sampling is a type of non-probability sampling that involves the sample being drawn from that part of the population that is close to hand. In other words, convenience sampling is a non-probability sampling technique where subjects are selected because of their convenient accessibility and proximity to the researcher. The data were collected in Esfahan during the academic year of 2020-2021. The sample was selected based on the homogeneity of participants in their economic, social, educational, and cultural characteristics. Thanks to the point that the 'Department of Education, District 1' in Esfahan belonged economically, socially, educationally, and culturally to the middle class, it was referred to as the targeted district and all parents whose children have one of the three types of ND, namely, ASD, ID, and ADHD, were invited to take part in the research. As a result, 57 parents of children with ASD, 57 parents of children with ID, and 52 parents of children with ADHD who met the inclusion criteria were selected as the participants of the study. The criterion for diagnosing ID for a child in Iran is a score of 55 to 70 on the Wechsler, Leiter, and Goodenough scales. In addition, clinical observations and interviews with parents should also confirm the above results. The criterion for diagnosing ASD in Iran is that the child's performance is measured using the Autism Diagnostic Interview-Revised (ADI-R) test in the three areas of communication, interaction, and stereotyped behavior. If a child's performance in all three areas is below the average performance of students of the same age, the child is diagnosed as having an ASD. In addition, clinical observations and interviews with parents should also confirm the above results. The criterion for diagnosing ADHD in Iran is that the child's performance is measured using attention-related subscales in the Wechsler and Leiter scales. In addition, clinical observations and interviews with parents should also confirm the above results. It is worth noting that the assessment Office of the Exceptional Education Department in Esfahan, recognizes children with ASD, ID, and ADHD based on the above criteria.

The inclusion criteria for entering the research were having a child with ASD (ASD without ID and no other additional disability and can communicate verbally, Mean age (years) = 9.912), ID (IQ between 55 and 70, no other additional disability and can communicate verbally, Mean age (years) = 10.210), and ADHD (no other additional disability and can communicate verbally, Mean age (years) = 10.269) with a child aged between 7 and 12 and signing the consent form for participation in the research. People who did not meet the mentioned criteria were excluded from the study.

The sample characteristics of the parents of children with ASD, parents of children with ID, and parents of children with ADHD were examined. There were no significant differences between the three groups in terms of the mean age (by ANOVA test), educational level (by Chi-squared test), the mean age of children with disability (by ANOVA test), gender of children with disability (by Chi-squared test), birth order of children with disability (by ANOVA test), family size (by ANOVA test), and family income (by Chi-squared test).

This study was comprised of a total of 166 participants. 57 parents of children with ASD (females,  $n = 42$ ; males,  $n = 15$ ), 57 parents of children with ID (females,  $n = 38$ ; males,  $n = 19$ ), and 52 parents of children with ADHD (females,  $n = 33$ ; males,  $n = 19$ ). It is worth noting that there were no significant differences between the three groups in terms of the gender of parents (by Chi-squared test).

### **Instrument**

#### **Medical outcomes study social support survey (MOS-SSS)**

This scale was originally developed by Sherbourne and Stewart (1991). The MOS-SSS is designed for adults, ages 18 and older and measures the availability of support, if needed, in several domains. It features 19 items and 4 subscales. There are 4 items under the tangible support subscale (e.g. "Someone to help you if you were confined to bed"), 3 items under the affectionate subscale (e.g. "Someone who shows you love and affection"), 4 items under the positive social interaction subscale (e.g. "Someone to get together with for relaxation"), and 8 items under the emotional or informational support subscale (e.g. "Someone you can count on to listen to you when you need to talk"). The scale is a 5-point Likert scale, including none of the time(1), a little of the time(2), some of the time(3), most of the time(4), and all of the time(5). The higher the score, the better the perception of social support. The total scale was calculated by adding all responses (range 19–95). Researchers reported high internal consistency for different dimensions of the scale including tangible support (.91), emotion/information support (.96), affection support (.94), positive social interaction (.94), and total support (.93). The measure possesses good convergent and divergent validity. There is also good evidence of test-retest reliability and stability over time (Sherbourne and Stewart 1991). In addition, the validity and reliability of this scale have been confirmed by various researchers (Din *et al.* 2020, Dafaalla *et al.* 2016, Shyu *et al.* 2006, Anderson *et al.* 2005, Mahmud *et al.* 2004, Yu *et al.* 2004). In this research, The Cronbach alpha for the total MOS-SSS was 0.89, and for the subscales of tangible support, emotion/information support, affection support, and positive social interaction; 0.74, 0.86, 0.72, and 0.71, respectively. It should be noted that the participants

were asked to complete the paper and pencil version of MOS-SSS individually at school, and it took them about 10-15 min to complete it.

**Ethical considerations**

Parents gave consent for their participation in this study. The participants were aware of the purpose of the study and they had the right to leave the study at any time if they wished so. The participants were also assured that all their information would remain confidential. The ethical review board of the regional Special Education Organization approved the study.

**Results**

Table 1 presents the total score of social support of subjects based on parents’ group and parents’ gender.

A two-way ANOVA test was used to compare the mean score of social support based on parents’ group (parents of children with ASD, parents of children with ID, and parents of children with ADHD (and parents’ gender (Male and Female). Before conducting Two-way ANOVA, Levene’s test was used to examine the assumption of homogeneity of variances. The result of Levene’s test was not significant, thus, Two-way ANOVA could be conducted.

The Two-way ANOVA results showed no significant difference in terms of social support between parents based on parents’ group (parents of children with ASD, parents of children with ID, and parents of children with ADHD ( $F = 1.773, p > 0.05$ ), parents’ gender (Male and Female) [ $F = 2.930, p > 0.05$ ] and interaction between parents’ group and parents’ gender [ $F = 0.339, p > 0.05$ ].

Moreover, Table 2 presents the mean score of subscales of social support of subjects based on parents’ group and parents’ gender.

MANOVA test was used to compare the mean score of subscales of social support based on parents’ group (parents of children with ASD, parents of children with ID, and parents of children with ADHD (and parents’ gender (Male and Female). Before conducting MANOVA, Levene’s test was used to examine the assumption of homogeneity of variances. The result of Levene’s test was not significant, thus, MANOVA could be conducted. Furthermore, to study the homogeneity of covariance matrices, Box’s M test was used. The results showed that its value was not significant. Therefore, it was concluded that the variance-covariance matrix of the dependent

variables was equal in all groups. The results of MANOVA showed that the effects obtained for the parent groups were not significant regarding the subscales of emotional/informational support [ $F = 0.626, p > 0.05$ ], tangible support [ $F = 2.219, p > 0.05$ ], and affectionate support [ $F = 0.988, p > 0.05$ ], but the effects obtained for the parent groups were significant regarding the subscale of positive social interaction [ $F = 6.510, p > 0.001$ ]. Moreover, the results of MANOVA showed no significant difference in subscales of emotional/informational support [ $F = 1.124, p > 0.05$ ], tangible support [ $F = 2.724, p > 0.05$ ], and affectionate support [ $F = 2.270, p > 0.05$ ], and positive social interaction [ $F = 2.280, p > 0.05$ ] between parents based on parents’ gender (Male and Female). Therefore, Scheffe’s post-hoc test was used to investigate the differences between the means of the groups in the subscale of positive social interaction. The results are presented in Table 3.

The results showed a significant difference between the parents of children with ASD and parents of children with ID in terms of positive social interaction ( $p < .01$ ). This means that the positive social interaction was higher among the parents of children with ID compared to those among the parents of children with ASD. The results also revealed a significant difference between the parents of children with ID and parents of children with ADHD in terms of ASD ( $p < .01$ ). That is to say, parents of children with ID had more positive social interaction than the parents of children with ADHD. There were no significant differences between the parents of children with ASD and parents of children with ADHD in terms of positive social interaction ( $p > .05$ ).

**Discussion**

The aim of this study was to compare the social support and its subscales in parents of children with NDD (parents of children with ASD, parents of children with ID, and parents of children with ADHD) based on the gender of the parents.

The results showed that there was no significant difference in the total score of social support between parents of children with NDD based on the type of child disorder. Explaining this finding, it can be stated that several studies showed that among all three groups of children with ASD, children with ID, and children with ADHD, there were emotional, social, communicational, and behavioral problems (Kristoffersen *et al.* 2015, Muggleton *et al.* 2019,

**Table 1. Mean and standard deviation of total score of social support of subjects based on parents’ group and parents’ gender.**

| Parents’ gender<br>Parents’ group | Male   |        | Female |        | Total  |        |
|-----------------------------------|--------|--------|--------|--------|--------|--------|
|                                   | M      | SD     | M      | SD     | M      | SD     |
| Parents of Children with ASD      | 46.866 | 7.670  | 42.619 | 10.205 | 43.736 | 9.722  |
| Parents of Children with ID       | 49.578 | 10.073 | 46.736 | 9.977  | 47.684 | 10.010 |
| Parents of Children with ADHD     | 48.210 | 8.107  | 47.181 | 8.797  | 47.557 | 8.486  |
| Total                             | 48.320 | 8.655  | 45.336 | 9.877  | 46.289 | 9.580  |

**Table 2. Mean and standard deviation of subscales of social support of subjects based on parents' group and parents' gender.**

| Parents' gender                 | Subscales | Parents' group                | Male   |       | Female |       | Total  |       |
|---------------------------------|-----------|-------------------------------|--------|-------|--------|-------|--------|-------|
|                                 |           |                               | M      | SD    | M      | SD    | M      | SD    |
| Emotional/informational Support |           | Parents of Children with ASD  | 20.266 | 3.807 | 18.595 | 5.392 | 19.035 | 5.046 |
|                                 |           | Parents of Children with ID   | 20.421 | 4.574 | 19.184 | 5.331 | 19.596 | 5.084 |
|                                 |           | Parents of Children with ADHD | 20.368 | 3.515 | 20.697 | 4.700 | 20.576 | 4.271 |
| Tangible Support                |           | Parents of Children with ASD  | 10.200 | 2.426 | 8.88   | 2.471 | 9.228  | 2.507 |
|                                 |           | Parents of Children with ID   | 10.631 | 3.148 | 9.368  | 2.098 | 9.789  | 2.541 |
|                                 |           | Parents of Children with ADHD | 11.315 | 2.829 | 10.030 | 2.899 | 10.500 | 2.914 |
| Affectionate Support            |           | Parents of Children with ASD  | 8.666  | 1.799 | 7.595  | 2.220 | 7.877  | 2.155 |
|                                 |           | Parents of Children with ID   | 8.631  | 2.060 | 8.473  | 2.023 | 8.526  | 2.019 |
|                                 |           | Parents of Children with ADHD | 8.157  | 2.007 | 7.878  | 1.654 | 7.980  | 1.777 |
| Positive social interaction     |           | Parents of Children with ASD  | 6.533  | 1.598 | 6.119  | 1.953 | 6.228  | 1.861 |
|                                 |           | Parents of Children with ID   | 8.000  | 2.134 | 7.315  | 1.876 | 7.543  | 1.974 |
|                                 |           | Parents of Children with ADHD | 6.842  | 1.834 | 6.515  | 1.770 | 6.634  | 1.783 |

Note. ASD = Autism Spectrum Disorder, ID = Intellectual Disability, ADHD = Attention Deficit/Hyperactivity Disorder.

**Table 3. The results of the scheffe post hoc test for subscales.**

| Dependent Variable          | (I) Group( $\bar{x}$ )                           | (J) Group( $\bar{x}$ )                           | Mean Difference (I-J) | Sig. |
|-----------------------------|--|--|-----------------------|------|
| Positive social interaction | Parents of Children with ASD( $\bar{x}$ =6.228)  | Parents of Children with ID( $\bar{x}$ =7.543)   | -1.315                | .001 |
|                             | Parents of Children with ID( $\bar{x}$ =7.543)   | Parents of Children with ADHD( $\bar{x}$ =6.634) | .909                  | .044 |
|                             | Parents of Children with ADHD( $\bar{x}$ =6.634) | Parents of Children with ASD( $\bar{x}$ =6.228)  | .406                  | .498 |
|                             |  |  |                       |      |

Zen *et al.* 2019). Although specific behaviors may vary between groups, the result looks the same. That is, these challenges lead to parental isolation and reduced family and social interactions, resulting in reduced parental social support (Grant *et al.* 2013). Probably for these reasons, there was no significant difference in terms of the total score of social support between parents of children with NDD based on the type of child disorder.

The results showed that there was no significant difference in the total score of social support between parents of children with NDD based on the gender of the parents. Explaining this finding, it can be said that both father and mother of children with NDD were likely to participate in the care and education of children with NDD regardless of the child's disorder and therefore there was no significant difference in social support between parents of children with NDD based on the gender of the parents.

There are similar stressors for parents of children with NDDs, such as community labels, medical, educational, and transportation costs, parents' concerns about their child's future, and finding the treatment center to follow up on their child's health (Nidiffer and Kelly 1983). In addition, the child's behavioral, emotional, and social problems are factors that cause anxiety and challenge for parents lead to isolation and reduced parental relationships, family travel, and social gatherings (Mickelson 2001). Probably because the conditions are the same for parents, so there is no significant difference in the total score of social support between parents of children with NDD based on the type of child disorder and the gender of the parents.

Moreover, the results showed that there was no significant difference in the 3 subscales of social

support (i.e. emotional/informational support, tangible support, and affectionate support) between parents of children with NDD but there was a significant difference in the subscale of social interaction between parents of children with NDD. It means the rate of social interaction between parents of children with ID was significantly higher than parents of children with ASD and parents of children with ADHD. In explaining the more social interaction between parents of children with ID than parents of children with ASD and parents of children with ADHD, it can be argued that children's distress, inability to understand discipline, resistance, stubbornness and aggression, impulsive behavior as well as communication problems cause conflict between the child and parents, which include the isolation of family and reduced social interactions with friends and acquaintances (Francis 2012, Muggleton *et al.* 2019). Behavioral and emotional problems are more common in children with ASD and children with ADHD than in children with ID, which allows parents to feel helpless to control and manage their child's behaviors (Goedeke *et al.* 2019). This feeling of helplessness reduces the social interactions of these parents (Goedeke *et al.* 2019).

The results showed that there was no significant difference in affectionate support between parents of children with NDD. In Explaining this finding, it can be stated that parenting style is a factor influencing the level of parental affection of these children and research has shown that parents of NDDs mainly use authoritarian parenting style in raising their children. The result of this type of parenting style is low parental affection (Domitrovich and Bierman 2001), so, there was no significant difference in the affectionate support between the parents of children with ID, parents of children with ASD, and parents of

children with ADHD which probably refer to the use of authoritarian parenting styles in all three groups.

There was also no significant difference in the emotional/informational and tangible support between the parents of children with ID, parents of children with ASD, and parents of children with ADHD. Explaining this finding, it can be stated that since all children with special needs were trained in the research samples present in daycare centers, so all children and their parents had the same services, training, and support. There was probably no significant difference between the parents of the three groups in the emotional/informational support and tangible support due to receiving the same information support, emotional support, and tangible support.

The results showed that there was no significant difference in subscales of social support between parents of children with NDD based on the gender of the parents. Explaining this finding, it can be stated that formal and informal support for parents of children with NDD is probably the same (Goedeke *et al.* 2019). Thus, the lack of significant differences in subscales of social support between parents of children with NDD based on gender may be due to similar problems and challenges (Lindsey *et al.* 2020) and the same services, training, and support (Nava *et al.* 2020, Dieleman *et al.* 2018, Goedeke *et al.* 2019). While social support for people with disability and their family is very important in western countries (Goedeke *et al.* 2019, Mitchell *et al.* 2016, George *et al.* 2011, Langeland and Wahl 2009, Shin 2002), this is not the case for people with disabilities and their family in Iran (Forouzan *et al.* 2013, Savari *et al.* 2021, Hemati Alamdarloo *et al.* 2019).

In this study, only a questionnaire was used to collect data, it is suggested to use an interview to collect data in addition to a questionnaire in future studies. Data collection of this study and the education of these children was done virtually by parents because it was associated with the period of the Coronavirus pandemic with the restrictions imposed on the public and also parents spending more time in contact with NDD children could affect the results of the data, and caution should be exercised in generalizing it to the pre-and post- Coronavirus pandemic. Therefore, according to the research findings, it is suggested that the causes of the decrease in parents' social support as well as ways to increase it should be investigated. It is also necessary that supportive and educational programs, especially with the aim of increasing social interactions and leisure of parents of children with ASD and ADHD should be on the agenda of organizations responsible for the welfare and mental health.


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## Disclosure statement

No potential conflict of interest was reported by the authors.

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