

Predictors of Advocacy in Parents of Children with Autism Spectrum Disorders

Abstract

The purpose of the study was to investigate the predictors of advocacy in parents of children with autism spectrum disorder. The role of advocacy as it relates to stressors, resources, and perceptions was explored using the Double ABCX model as a theoretical framework. A total of 28 participants were included. Correlation and mediated regression analyses were used to examine the relationships among variables within the theoretical framework. Results show that use of maladaptive coping strategies was a significant predictor of current levels of advocacy, which suggests that advocacy may itself be an active coping strategy for parents. Implications of the results and directions for future research are discussed.

The diagnosis of a child's disability can have unexpected life-altering effects for parents. For some parents, it may be the catalyst for a variety of mental health challenges, including symptoms of anxiety and depression, as the stress of caring for a child with a disability can be taxing (Bromley, Hare, Davison, & Emerson, 2004; Koegel et al., 1992). Parents of children with autism spectrum disorders (ASD) report experiencing more parenting stress and mental health problems (Blacher & McIntyre, 2006; Eisenhower, Baker, & Blacher, 2005) including symptoms of anxiety (Hastings, 2003) and depression (Feldman, Hancock, Reilly, Minnes, & Cairns, 2000), compared to parents of children with other disabilities. Recent research, however, has demonstrated that parents also report positive effects of caring for a child with a disability, such as personal growth or a sense of purpose (Hastings & Taunt, 2002). These "positive perceptions" are conceptualized as strategies that help the family cope and adapt to their situation. Furthermore, it has been found that experiencing stress does not preclude a family from also experiencing the positive effects associated with caring for their child (Hastings & Taunt, 2002).

Research on coping has highlighted the role of active problem-solving, as opposed to emotion-focused coping in positive adaptation to stress (Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). In this sense, parent advocacy for a child with a disability may be considered to be an active form of coping. Munro (1991) defined effective advocacy as "a non-violent empowerment and support process, through which families with disabled relatives can constructively express dissatisfaction and contribute creative solutions to problems existing in human service systems" (p. 1). That is, advocacy may

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involve activities such as information seeking and problem solving. In addition, parents may become involved in public education, political activism and speaking on behalf of their child or other children with disabilities.

In order to advocate effectively, parents need to educate themselves to gain an understanding of the relevant social, economic, and political environments, and become familiar with philosophies of service delivery, legislation, and budgetary issues. Parents may not only be advocates, but also disability experts, strategists, and agents for systemic change (Trainor, 2011). In particular, parents of children with ASD have a history of being strong advocates for service delivery for their children (Minnes & Burbidge, 2011). The purpose of this study was to explore the use of advocacy by parents of children with ASD, where advocacy was defined as any action taken by a parent on behalf of their child or other children with ASD to ensure adequate support, proper level of care, and basic human rights.

Although parents have lobbied for educational and healthcare supports for their children with disabilities for decades, advocacy is a relatively new research area. Little is known about the factors that contribute to advocacy, such as parent characteristics, or the factors that increase the likelihood of successful advocacy. A qualitative study by Nachshen and Jamieson (2000) explored the role of advocacy in relation to parental well-being. The results indicated that outcomes related to advocacy could be positive (e.g., inspiring feelings of confidence and empowerment), but also negative (e.g., contributing to depression, guilt, and anxiety).

Given the need for further research in this area, the purpose of this study was to explore involvement in advocacy related activities by parents of children with ASD, and to investigate predictors of parent advocacy. The Double ABCX Model of Adjustment and Adaptation (McCubbin & Patterson, 1983) has been frequently used to examine the adaptation of families of children with developmental disabilities (DD) (Hassall & Rose, 2005). The model highlights the need to consider the contributions of child characteristics, family resources, parents'

perceptions, and coping to both positive and negative family outcomes. For purposes of this research, the Double ABCX model was used as a theoretical framework to guide variable selection for investigating advocacy as an approach to managing the challenges involved in raising a child with an ASD (Figure 1). It was hypothesized that parents' stressors, resources, and perceptions would be related to advocacy.

Method

Participants

The study was approved by the General Research Ethics Board at Queen's University. Twenty-eight mothers ranging in age from 30 to 53 years ($M = 43.89$; $SD = 6.21$) were included in this study. Seventy-nine percent of participants were married ($n = 22$), the others were single ($n = 1$), divorced ($n = 4$), or living in common-law relationships ($n = 1$). Many of the mothers lived in Canada (60.7%; $n = 17$) and the United States (39.3%; $n = 11$). They were a highly educated group with 75% of participants ($n = 21$) having an undergraduate or graduate university degree, and reported an average household income of approximately \$87,000 ($SD = \$53,395$, range: \$20,000–\$250,000).

The children of participating parents ($n = 28$) ranged in age from 6 to 19 years ($M = 11.21$; $SD = 4.20$). They were primarily diagnosed with an autistic disorder (28.60%; $n = 8$), Asperger syndrome (10.70%; $n = 3$), pervasive developmental disorder-not otherwise specified (17.90%; $n = 5$) and ASD (7.10%; $n = 2$), with the remaining participants having a combination of diagnoses.

Measures

For the purposes of the present study, the components of the second half of the Double ABCX model (Figure 1) were used. That is, the first half of the model is theoretically linked to the initial crisis and adjustment period after the birth of a child with ASD, and the second half of the model is linked to the adaptation, which in this study refers to parental advocacy.

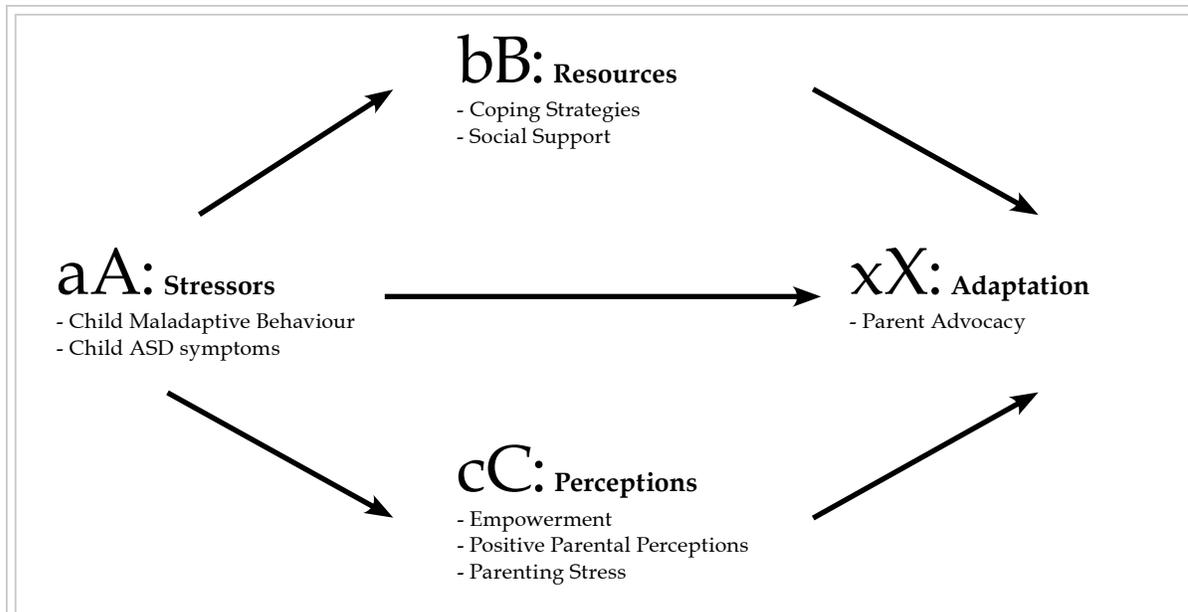


Figure 1. Double ABCX Model as a theoretical framework

The Double ABCX model incorporates two halves: one half represents adjustment and the second half represents the adaptation. The first half focuses on adaptation to an initial crisis (which is often conceptualized as the adjustment period after the birth of a child with a developmental disability). For this study, we are only using the second half of the model because theoretically our parents have already progressed through the first half, which is why we use aA, bB, cC, xX rather than A, B, C, X. (Adapted from McCubbin & Patterson, 1983)

Stressors (aA Factor)

Demographics

Information was collected including: the child’s date of birth, diagnosis, gender, the family constellation, parent’s education level, and use of support services.

Social Communication Questionnaire

The Social Communication Questionnaire (SCQ; Rutter, Bailey, & Lord, 2003) uses parental report to screen for symptoms of ASD. Parents responded to 40 yes or no questions regarding their child’s functioning over the past three months. The SCQ has been found to have good sensitivity, $\alpha = .71$ (i.e., a higher rate of correct identifications), with a cut-off of 15 for children with a mean age of 5 years (Eaves, Wingert, Ho, & Mickelson, 2006). For the purposes of this study, the cut-off score of 15 was used. The SCQ was used to screen participants for inclusion, and to measure severity of ASD symptoms.

Scales of Independent Behaviour-Revised Short Form

The Scales of Independent Behaviour-Revised Short Form (SIB-R SF; Bruininks, Woodcock, Weatherman, & Hill, 1996) was used to assess adaptive and maladaptive behaviour. Parents rated their child’s ability to perform 40 tasks independently, using a 4-point scale from 0 (never or rarely) to 3 (does very well always or almost always - without being asked). Parents also rated the frequency and severity of eight types of problem behaviour. These scores were used to calculate general, internalized, asocial, and externalized maladaptive behaviour scores. Scores from 10 to -10 are considered to be within the “normal range,” -11 to -20 are “marginally serious,” -21 to -30 are “moderately serious,” -31 to -40 are “serious,” and scores lower than -41 are “very serious.” The SIB-R has been standardized, and has good internal consistency ($\alpha = .84-.98$ in a normative sample, $\alpha = .98-.99$ in children with intellectual disabilities), high test-retest reliability, and good inter-rater reliability ($r = .78-.95$ in a normative sample, $r = .57-.85$ in children with

intellectual disabilities) (Bruininks et al., 1996; Winters, Collett, & Myers, 2005).

Resources (bB Factor)

Brief COPE

The Brief COPE (Carver, 1997) was adapted from the COPE (Carver, Scheier, & Weintraub, 1989) and uses 28 items to measure participants' use of 14 types of coping strategies. These strategies include: active coping, planning, positive reframing, acceptance, humour, religion, using emotional support, using instrumental support, self-distraction, denial, venting, substance use, behavioural disengagement and self-blame. Participants rated their use of each coping strategy on a 4-point scale from 0 (I haven't been doing this at all) to 3 (I've been doing this a lot). Reliability has been found to be relatively good (from $\alpha = .50$ to $\alpha = .90$) (Carver, 1997). The 14 coping strategies from the Brief COPE can be grouped into adaptive and maladaptive coping styles, with adaptive strategies including: active coping, planning, positive reframing, acceptance, humour, religion, use of emotional support and use of instrumental support, and maladaptive coping strategies including: self-distraction, denial, venting, substance use, behavioural disengagement, and self-blame (Meyer, 2001).

Types of Support Questionnaire

The Types of Support Questionnaire (TOS; McColl & Skinner, 1995) is a measure of social support adapted from the Interpersonal Support Evaluation List (ISEL; Cohen & Hoberman, 1983). It includes 25 questions from three categories of support: instrumental, informational, and emotional. Instrumental support refers to those supports that directly address the source of a problem, for example "If I needed a quick emergency loan of \$100, there is someone I could get it from." Informational support refers to the advice, guidance, and information that help one achieve a different perspective on a problem, for example, "there is someone who can give me objective feedback on how I'm handling things." Emotional support refers to inputs directed at moderating the emotional reaction to a problem, for example, "There is someone with whom I can share my

most private worries and fears." Participants were asked to rate the perceived availability of support from 0 (never true) to 3 (always true), with a "not applicable" option as well for each question. A total score was calculated with higher scores indicating more perceived support. There are also three questions assessing satisfaction with each type of support.

Perceptions (cC Factor)

Kansas Inventory of Parental Perceptions

The Kansas Inventory of Parental Perceptions (KIPP; Behr, Murphy, & Summers, 1992) measures parent perceptions in several domains including: positive contributions, social comparisons, causal attributions, and mastery/control. The current study included the Positive Contributions and Mastery/Control subscales of the KIPP. The Positive Contributions subscale measures the perception that the family member with a disability has had a positive effect on the rater's life. The following themes are included in the items: learning through experience with special problems in life, happiness and fulfillment, strength and family closeness, understanding life's purpose, awareness about future issues, personal growth and maturity, expanded social network, career/job growth, and pride and cooperation. The Mastery/Control subscale measures the perception that one has control over the situation or the power to influence outcomes for the family member with a disability, items are related to: personal control and professional control. For the Positive Contributions subscale, participants were required to rate each item on a 4-point scale in terms of how much they agree or disagree from 1 (strongly disagree) to 4 (strongly agree), with higher scores on the scale indicating a greater level of agreement. On the Mastery/Control subscale participants rated their perception of how much control they and professionals have over outcomes for their child with a disability from 1 (none) to 4 (a lot), with higher scores indicating a greater perception of control. All subscales of the KIPP have been found to possess good internal consistency (mean $\alpha = .66-.87$). Construct validity has been found through both factor analysis and correlational analysis; however, subscale scores have not been found to be stable as parent's percep-

tions change over time (KIPP; Behr, Murphy, & Summers, 1992). For the current study the Mastery/Control subscale was used as a measure of empowerment, as it reflects parents' perceptions of their own ability to influence services and outcomes for their child, whereas the Positive Contributions was used as a measure of positive parental perceptions.

Family Stress and Coping Interview

The Family Stress and Coping Interview (FSCI; Nachshen, Woodford, & Minnes, 2003) was used to measure perceived stress and coping in caregivers of individuals with DD. For the current study, the questions related to coping were not asked. Parents were asked to rate 23 issues in terms of stressfulness on a 4-point scale ranging from 0 (Not Stressful) to 3 (Extremely Stressful). Items include a number of issues such as, child diagnosis, integration, and personal needs, among others. Individual items can be summed to create a total stress score, with higher scores indicating a higher level of perceived stress. The FSCI has been found to have high internal consistency ($\alpha = .89$), high test-retest reliability ($r = .8$), and face validity (Nachshen et al., 2003).

Adaptation (xX Factor)

Parent Advocacy Scale

The Parent Advocacy Scale (PAS; Nachshen, Anderson, & Jamieson, 2001) uses 26 items to assess parents' current level of advocacy. Participants rated their level of advocacy in the past nine months; however, for purposes of the current study participants were asked about their experiences in the past 12 months, as data collection took place over a one-year period. Categories include: phone calls, office visits or meetings, letters and mass mailings, media reports, and other activities. Within each category participants reported the number of actions, the focus of the action (i.e., whether the action was undertaken for their child or for individuals with DD in general), their participation and level of involvement in organizations, and the role of advocacy in their life. Items include both open and closed-ended responses to allow participants to clarify any answers. Participants were asked about their

participation in organizations, as well as the role of advocacy in their life. Two independent raters then scored responses from 0 to 4 for each dimension spanning the five categories. Scores can range from 0 to 20 in total with higher scores indicating a greater level of participation in advocacy activities. This measure has been shown to have good internal consistency ($\alpha = .87$). For this study, reliability between raters was found to be high ($\alpha = .98$).

Procedure

Participants who had previously participated in a study on parent support group participation, and consented to being contacted for future research were contacted by email and invited to complete the PAS for the current study. Data from other measures used in this study were gathered approximately 12 months prior to completing the PAS. All of the questionnaires were completed using a secure online program.

Participation was limited to those who completed all surveys from the initial study ($n = 149$). Fifty-one participants completed the advocacy survey online, 15 participants were excluded due to missing data, eight participants were excluded as their children did not meet the cut-off for ASD on the screening measure (i.e., SCQ) ($n = 28$). Participation in the initial study took approximately one hour, and the current study took approximately 15 minutes. Participants had the option to enter a lottery for one of two gift cards.

Statistical Analysis

Correlation and mediated regression analyses were used to examine the relationships among variables within the theoretical framework. Results of analyses were interpreted at the 95% confidence level ($\alpha = .05$).

Results

Stressors (aA)

Of the 28 participants included in the study, on average, few maladaptive behaviours were reported on the SIB-R SF, with scores on the general maladaptive index in the nor-

mal to marginally serious range ($M = -18.22$; $SD = 11.13$), and moderate symptoms of ASD on the SCQ ($M = 19.47$; $SD = 5.69$).

Resources (bB)

Participants reported frequently using adaptive coping methods on the Brief COPE. The most frequently used were: active coping ($M = 6.92$; $SD = 1.39$), planning ($M = 6.68$; $SD = 1.47$), and acceptance ($M = 6.68$; $SD = 1.52$), with moderate scores on instrumental support ($M = 5.39$; $SD = 1.45$), and reframing ($M = 5.32$; $SD = 2.16$). Moderate scores on maladaptive coping strategies were also reported, the most frequently reported were: self-blame ($M = 4.14$; $SD = 1.76$), and venting ($M = 4.14$; $SD = 1.41$). Mothers reported experiencing a moderate level of emotional support ($M = 23.82$; $SD = 9.00$), low levels of informational support ($M = 10.86$; $SD = 4.85$), and low levels of instrumental support ($M = 12.00$; $SD = 5.70$) on the TOS Questionnaire.

Perceptions (cC)

Participants reported moderately high scores on positive perceptions of their children on the KIPP including: viewing their children as source of learning ($M = 23.07$; $SD = 3.08$), as a source of strength ($M = 22.29$; $SD = 4.48$), and as a source of happiness ($M = 20.07$; $SD = 3.46$), with moderate scores on viewing their children as a source of personal growth ($M = 19.25$; $SD = 4.90$), and pride ($M = 14.96$; $SD = 5.51$). Participants reported moderate levels of empowerment in terms of both personal ($M = 21.04$; $SD = 2.80$), and professional control ($M = 24.89$; $SD = 6.66$). Participants reported mild to moderate stress levels on the FSCI ($M = 37.25$; $SD = 12.81$).

Adaptation (xX)

Participants on average reported a moderately high score on the PAS ($M = 8.57$; $SD = 4.23$, score range = 2–17). Participants reported making more phone calls ($M = 3.60$; $SD = 1.96$) and office visits ($M = 3.10$; $SD = 1.94$), than mailings ($M = 2.03$; $SD = 2.36$) or media reports ($M = .80$; $SD = 1.34$), with a range of 0 to 5+ for the number of times each advocacy activity was performed. Participants reported being involved

in outside organizations ($M = 2.17$; $SD = 1.34$) in a number of different capacities from participant to organizational founder. Participants reported participating in each form of advocacy activity primarily for their own child with few participants additionally advocating for all individuals with DD as well. Sixty-one percent of participants ($n = 17$) reported feeling positive about the role of advocacy in their lives, while 82% ($n = 23$) felt they had the ability to change the quality of life of their child. However, some participants reported mixed feelings regarding advocacy when allowed to elaborate.

Predictors of Parents' Current Level of Advocacy

Correlational analyses were performed to determine which predictors to include in the regression model. In order to determine predictors of parent advocacy the relationships between the following variables and advocacy were investigated: stressors (aA factor): child maladaptive behaviour, child ASD symptoms; resources (bB factor): social support, parent coping; perceptions (cC factor): empowerment, parent stress, positive perceptions. Results are shown in Table 1.

Maladaptive coping (bB), and emotional support (bB) emerged as the only significant correlates of parent's current advocacy scores (xX) ($r = -.44$, $p < .05$, and $r = .39$, $p < .05$). A simultaneous multiple regression analysis was then conducted to evaluate the relative contributions of maladaptive coping strategies, and emotional support to parents' current level of advocacy (xX). The linear combination of predictors was significantly related to parent advocacy, $F(2, 25) = 5.35$, $p < .05$, and accounted for 30% of the variance in parent advocacy ($R^2 = .55$). Maladaptive coping (bB) emerged as the only significant predictor of parent current level of advocacy, such that greater use of maladaptive coping strategies (e.g., venting, denial) was related to less advocacy ($R^2 = .88$, $F(2, 25) = 5.35$, $p < .05$).

Discussion

Parents of children with ASD are required to advocate for social, financial, educational, and healthcare supports for their child throughout their child's life. Despite the regularity with

Table 1. Correlations Among Predictor (aA, bB, cC) Variables and Adaptation (xX) Variable

	PAS ^a
Child Age	.15
ASD Symptoms	-.01
Maladaptive Behaviour	.17
Maladaptive Coping	-.44*
Adaptive Coping	-.15
Emotional Support	.39*
Informational Support	.35
Instrumental Support	.26
Positive Parent Perceptions	.01
Parenting Stress	-.27
Empowerment – Professional Control	.02
Empowerment – Personal Control	-.22

^a Parent Advocacy Scale; * $p < .05$. ** $p < .01$.

which parents advocate, very little is known about parent's perceptions of their need to advocate or the predictors of successful advocacy. This study investigated advocacy as an adaptation to the stress related to parenting a child with ASD. In addition, the study explored predictors of advocacy. Results demonstrated a range of parent advocacy actions in each of the advocacy categories. It was found that parents reported a greater number of phone calls and office visits. Whether or not these forms of advocacy lead to a more successful result requires more research. Additionally, parents reported involvement in a range of organizations, with some parents reporting a change of career as a result of advocating for their child, while others reported a very low level of involvement. Further research should investigate parent personality traits and their effect on perceptions of and engagement in advocacy actions, as there may be a link between perceptions of success, and further involvement in such activities.

Over 60% of parents reported positive feelings towards the role of advocacy in their lives. In addition, the majority of parents reported perceiving that they had the ability to change the quality of life for their child. These results indicate that although advocacy can be difficult at times, many parents feel that advocacy is neces-

sary to help improve their child's life. Whether or not the outcomes of advocacy influenced parents' perception of their ability to advocate is still not known.

Maladaptive coping (bB) was found to be a significant predictor of current levels of parent advocacy (xX), such that the greater use of maladaptive coping strategies (bB) was negatively correlated with higher levels of parent advocacy (xX). Although a relationship between use of adaptive coping strategies and advocacy was not found in the current study, a question for future research would be whether mothers who employ fewer maladaptive coping strategies, such as denial and self-blame, and focus on other coping mechanisms, such as problem-focused coping, in turn advocate more for their child.

The connection between maladaptive coping strategies and subjective levels of maternal well-being has been well established in mothers of children with a DD (i.e., greater use of maladaptive coping strategies was linked with lower perceived levels of well-being and adjustment; Glidden, Billings, & Jobe, 2006). Findings from the current study suggest that advocacy may itself be an active coping strategy for parents dealing with external stressors, such as child maladaptive behaviour, and severity of

ASD symptoms, however, further investigation is needed. This information could be particularly important for practitioners, as such findings could provide insight into the unique needs and challenges faced by caregivers of children with ASD.

Limitations and Future Directions

The PAS (Nachshen et al., 2001) has some limitations in terms of the subjectivity of scoring parents' advocacy actions. For example, in terms of the "Focus of Actions" scoring category, parents can only receive the highest score if their advocacy actions are at the national or international level on behalf of other individuals with DD, yet there is no opportunity within the survey for parents to discriminate between their involvement in organizations at these levels. Further research is needed to determine if one form of advocacy differs from another, or leads to more successful outcomes. Additionally, in the categories "Membership in Organizations" and "Activity Level in Organizations" scores are based on the number of advocacy organizations they are involved in, as well as their level of involvement within these groups. This section of the PAS is limited in that a participant with minimal involvement in several organizations may be given the same score as a participant who is extensively involved in one or two organizations. This is a substantial limitation as many participants are grouped together with similar ratings despite having a very different level of involvement in advocacy. Further research is needed to determine if there is a significant difference between participants' levels of involvement and their perceptions of their level of involvement in advocacy.

The time lapse between data collection at time one and time two posed difficulties in terms of inferring causality, as some participants indicated their advocacy may have changed over the course of 12 months as a response to changing life stressors. Given the delay in responding there is the possibility that participants may have forgotten or misattributed the effects of said stressors on their reported level of advocacy.

Due to the small sample size our analyses were limited in terms of the number of predictors that could be included in our model. Future studies should aim to include a number of

other predictors, including socioeconomic status and marital status, as potential factors that may influence advocacy rates. Additionally, the large participant age range posed challenges in terms of drawing conclusions. That is, the unique composition of our sample suggests that participants may have a variety of life experiences with which to apply learned strategies to stressful situations. Similarly, the large range in household income also suggests that the stressors faced by the sample could vary drastically. However, our conclusions are limited to the measures included in the initial study. Future studies should use a longitudinal approach to track advocacy and other stressors as they occur across a child's lifespan. Further, the incorporation of qualitative data collection could provide greater insight into the nature of experiences for a given sample. This information will provide insight into events that precede or provoke advocacy, maladaptive coping strategies, as well as parent's adaptation response to such stressors.

Conclusion

Parents' ongoing burden of responsibility caring for a child with ASD financially, emotionally, and physically, puts a significant strain on their psychological well-being. Additionally, the continued need to advocate for services for a child with ASD may exacerbate these stressors, unless parents have the support and resources to effectively cope. Findings from the current study highlight various important factors that may help to promote more positive outcomes for parents. The field of advocacy is an important area for further research, particularly the parent and environmental characteristics that contribute to greater advocacy, and differences in parents' perceptions of the need to advocate deserve further research attention. Additionally, this research promotes the need for sensitivity towards the challenges faced by those caring for a child with ASD. From a practitioner's standpoint, these findings emphasize the potential positive benefits associated with advocacy, and the need for promoting problem-focused coping strategies among parents.

Key Messages From This Article

People with disabilities: You deserve the same things as everyone around you. We need to find out how to better support you and your family.

Professionals: Parents' ongoing need to advocate for their children with developmental disabilities requires further investigation as this may be a burden for some individuals and a coping strategy for others.

Policymakers: Policies geared towards supporting parents of children with developmental disabilities are crucial in the ongoing battle to provide the proper supports and assistance for their children.

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