

Incorporating Respite Care as a Child Support Expense for Children with Autism Spectrum Disorder

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The philosophical premise of the Child Support Guidelines has always been to ensure that the children of divorced, separated or non-formed families are provided with adequate and fair financial support. The goal is for these children to be afforded the same opportunities as children of intact families with parents of similar financial means as their own parents.¹To achieve this goal, the Child Support Guidelines place considerable emphasis on specifically delineated numerical qualifiers, such as parental income, cost of health insurance and number of overnights as the basis upon which the presumed appropriate figure of financial support is calculated. The Child Support Guidelines, however, are based upon the presumed regular and anticipated needs of the average child in an intact family. The needs of a child with Autism Spectrum Disorder are seldom the same the average child upon which the Child Support Guidelines are based. As is often the case with children with special needs, there are frequently expenses not contemplated within a guidelines-based child support figure which are specific to the child.

While courts have the discretion to supplement a guideline-based child support award to include any expenses not contemplated within the guidelines, those considerations, again, are almost always based upon a numerical qualifier associated with a specific expense related to the child. Appendix IX-A of the Child Support Guidelines authorizes the incorporation of other expenses approved by the court which are incurred for a child with special needs that are not incurred by an average intact family. This authority, however, authorizes the incorporation of a quantifiable expense incurred for the child. What do we do if the quantifiable expense is not incurred directly for the benefit of the child with ASD, but rather, for the benefit of that child's primary caretaking parent? Specifically, when calculating a child support

award for a child with ASD, how does one effectively incorporate the cost of respite care for the parent?

Respite care or respite services is a form of care intended to provide the primary caregiver temporary relief from the demands of caring for an individual with disabilities during the times when the caregiver would normally be available to provide care. The service relieves family members from care for short periods of time. Unlike work-related child care, which is an approved expense to be shared among parents, respite care is not intended to provide regular care such as during work hours. Rather, respite care is intended to provide temporary care for the child with special needs such that their parent can enjoy a reprieve from their regular caregiving responsibilities. Respite care is intended to enable the primary caretaker to have the ability to go to the movies, run an errand or even go on vacation. In other words, the object of respite care is to provide a direct benefit or service to the parent, rather than the child with ASD.

When described as above, practitioners and the courts alike instinctively fail to appreciate the special needs parent's request for respite care as a necessary expense to be shared between parents. The Child Support Guidelines expressly limit the incorporation or sharing of child care expenses to the cost of work-related child care. There is no provision within the guidelines authorizing courts to allocate non-work-related child care expenses between parents. One can see how a court could easily rebuff the request of the parent of a child with ASD for contribution toward respite care so that they could go away for the weekend. After all, don't all parents feel stressed and overwhelmed? Don't all parents at some point or another want a break from their parental responsibilities? While this point may be well-taken, respite care for the parent of a child with autism is not a frivolous luxury. Such a cavalier dismissal of the special need parent's need for respite not only disregards the

reality of the increased caregiving duties of the special needs parent, but ultimately amounts to the deprivation of a service which has a direct benefit on the health and welfare of both the parent and the child with ASD.

A 2020 study by Research in Autism Spectrum Disorders found that parents of children with ASD disproportionately experienced symptoms of post-traumatic stress disorder when compared against a sample group of parents of neurotypical children. The study specifically found that 18.6% of the sample parents met the criteria for a provisional diagnosis of PTSD.² Parents of children with ASD often report higher levels of stress and poorer psychological well-being than parents of children with other developmental disabilities.³ Significant symptoms of depression and anxiety have also been found to be quite common among parents of children with ASD. The parents of children with ASD consistently report increased depressive symptoms and a higher prevalence of probable clinical depression or significant psychological distress when compared to parents of neurotypical children.⁴ Parents of children with ASD consistently reported higher levels of depression, anxiety, emotional distress, and a variety of other psychopathological dimensions.

Empirical studies show that the parents of children with ASD experience very real effects on their physical and emotional health as a result of their caregiving duties in the form of depression, anxiety and emotional distress. Respite care has been shown to be positively associated with reduced levels of stress amongst the parents of children with ASD. Respite care has been further shown to reduce caregivers' stress, enable caregivers to complete daily tasks, facilitate the long-term caregiving in the home, provide parents with time to spend with their other children, and help families to live "a more ordinary life."⁵

While the express purpose of respite care is to benefit the caretaker, there is ample evidence to show that a parent's access to respite care provides notable benefits to the child with ASD. A 2012 study found that temporary respite relief for caregivers goes a long way toward keeping kids and young adults with ASD mentally healthy. They found that families with children with ASD who demonstrate challenging behaviors and did not have

access to respite opportunities had an increased incidence of psychiatric hospitalizations.⁶ However, for every \$1,000 spent on respite care during the preceding 60 days, there was an 8% decrease in the odds of hospitalization in adjusted analysis.⁷ The benefits of respite care expand beyond just to the primary caretaker and the child with ASD. The reduced levels of stress experienced by primary caretakers as a result of access to respite care has also been shown to have benefits to the neurotypical siblings of the child with ASD.⁸

While many may argue that a strict interpretation of the Child Support Guidelines necessarily excludes the cost of respite care from being incorporated into a guidelines-based support award, such an argument demonstrates a narrow understanding of not only the needs of the child with ASD, but also the needs of the parent. NJSA 2A:34-23 specifically provides that the health of a parent is factor to be considered by the when determining that amount of child support. If the toll of a parent's caretaking responsibility for a child with autism is such that their mental and emotional health is being impacted, should not the cost of any available interventions available be viewed as a necessary expenses related to the child? As practitioners, it is our duty to effectively communicate and advocate these our client's circumstances and needs. It is in the best interest for all children, not just children with autism, that they have parents or caregivers who are emotionally present and psychologically available to provide for their care. Where the child's specific disability places such a burden on the primary caretaker that their mental and emotional well-being is compromised, whatever interventions are available to ease the burden should be implemented for the benefit of the child. Thus, the cost of these interventions should be included in a child support guidelines calculation. We as practitioners need to be able to comprehensively understand and effectively articulate why these interventions are a necessity rather than a luxury.

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Endnotes

1. Rule 5:6A , Appendix IX-A (1).
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