



# Complex Child E-Magazine

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## Are Caregivers Happy?

by Susan Agrawal

There is no denying that parenting a child with special needs, a disability, or complex medical issues is difficult.<sup>1</sup> The time required in and of itself can be overwhelming and stressful, not to mention the sleep deprivation that often comes with parenting kids with special needs. Add to that dealing with insurance companies, special education, doctors, therapists, and confronting difficult medical decisions on a frequent basis, and it seems that our lives as caregivers are tremendously complicated.

But complications aside, are we truly happy? I asked that very question to a group of 64 caregivers and was pleasantly surprised to find that most of us are usually or very happy with our lives. Even more interestingly, most of us are actually happier than we were before our children were born or came to live with us.

### Overall Happiness

Of the 64 caregivers surveyed, 39 (61%) said they are happier now as compared to their level of happiness before becoming a caregiver. 41 caregivers (64%) categorized themselves as usually or very happy now, 17 (26%) claimed they were somewhat happy, and only six (9%) were occasionally happy or not happy at all.

**Table 1: Overall happiness for caregivers with one or more child with special needs**

	<b>Happier</b>	<b>Less Happy</b>		<b>Usually or Very Happy</b>	<b>Somewhat Happy</b>	<b>Occasionally or Not At All Happy</b>
Overall	39 (61%)	25 (39%)		41 (64%)	17 (26%)	6 (9%)

### Happiness by Level of Disability

My next area of interest was to determine if the level of disability or need was related to a caregiver's perception of his or her own happiness. While it would stand to reason that the happiness of parents taking care of children who require the most care or have the most needs would be lower, this is not actually the case. The majority of all caregivers viewed themselves as usually or very happy, regardless of the level of disability of their

child. In fact, those who had children with the greatest needs were just as likely to view themselves as usually or very happy (11 or 65%) as those who parent children with minor health issues (6 or 67%) and those who care for children with some limitations (11 or 69%).

The only group that was more likely to rate themselves somewhat, occasionally, or not at all happy was those caregivers who parent children with moderate but significant limitations, such as autism, mild/moderate cerebral palsy, or significant cognitive impairment. These parents were more likely to be less happy than they were before having children (9 or 43%) and a greater proportion fell into the category of somewhat happy (8 or 38%). They consistently rated themselves less happy than even the caregivers of children who were the most disabled and completely dependent.

**Table 2: Happiness by level of disability**

	<b>Happier</b>	<b>Less Happy</b>		<b>Usually or Very Happy</b>	<b>Somewhat Happy</b>	<b>Occasionally or Not At All Happy</b>
<b>Healthy or minor health issues</b>	6 (67%)	3 (33%)		6 (67%)	3 (33%)	0 (0%)
<b>Some limitations</b>	10 (63%)	6 (38%)		11 (69%)	3 (19%)	2 (13%)
<b>Significant limitations</b>	12 (57%)	9 (43%)		12 (57%)	8 (38%)	1 (5%)
<b>Completely dependent on caregiver</b>	10 (59%)	7 (41%)		11 (65%)	3 (18%)	3 (18%)

While caregivers of completely dependent children with the highest level of disability did see a decline in happiness as compared to before they had children (7 or 41% were less happy), this decline was similar to those caregivers of children with slightly lesser disabilities, categorized as children with significant limitations. Parents of children with the greatest needs usually fell into one of two categories: quite happy or quite unhappy.

I found it interesting but not entirely surprising that the least happy group overall was not the parents of the children with the greatest disabilities, but of those with significant limitations. My hypothesis is that caregivers of the children with the greatest needs are forced by the level of their child's impairment to recognize their child as developing at his or her own rate, and they usually stop comparing their child to healthy peers. On the other hand, some caregivers of children with significant limitations still view their children in comparison to typically developing peers, which appears to lead to lower levels of happiness for this group. In other words, it may be easier to accept a child whose disability is so significant that the child can no longer be compared to his peers

than a child who attempts to do many things on his own but is significantly limited in his ability to do them.

This is not to say that all parents can be generalized in this way. There are definitely caregivers who have been emotionally devastated by the extreme level of disability of their children, while there are others who happily parent and accept children with lesser disabilities. And there are some parents of children with very mild impairments who are profoundly affected by their children's disabilities.

### **Happiness by Number of Children**

One final fact that I found interesting is that parents who have an only child with special needs tended to be less happier than those who had two children, even if both children had special needs. Caregivers of an only child with special needs had the lowest levels of happiness of any group, with only nine (45%) rating themselves as usually or very happy. In comparison, 16 (80%) with two children were usually or very happy, as were 16 (67%) of those with three or more children.

These data seem to indicate that having a second child, whether that child has special needs or not, increases the happiness of most caregivers. I am not sure the reason for this, but perhaps the second child requires the parent to split her attention and energy between the two children, not allowing her to dwell as deeply on the difficult aspects of parenting an individual child with a disability.

**Table 3: Happiness by number of total children**

	<b>Happier</b>	<b>Less Happy</b>		<b>Usually or Very Happy</b>	<b>Somewhat Happy</b>	<b>Occasionally or Not At All Happy</b>
<b>1</b>	9 (45%)	11 (55%)		9 (45%)	8 (40%)	3 (15%)
<b>2</b>	13 (65%)	7 (35%)		16 (80%)	3 (15%)	1 (5%)
<b>3 or more</b>	16 (67%)	8 (33%)		16 (67%)	6 (25%)	2 (8%)

### **Are We Happy?**

This survey proves to us what so many parents of children with special needs already know: parenting our children gives us joy and makes the majority of us happy. Our children are truly wonderful gifts who have blessed our lives, and despite how difficult it can be to parent them, the majority of us are happy and thankful to have that honor.

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<sup>1</sup> I use the terms “caregiver” and “parent” interchangeably here. The survey discussed in this article includes parents, grandparents, foster parents, guardians, and other official caregivers. Therefore, the term “parent” is not used to represent a biological parent only, but any individual who acts as the primary caregiver for a child.