



## Family-Outcomes of Long-term Supports and Services for Family Members with Intellectual and Developmental Disabilities

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### Overview



For this report we looked at parents' self-reported experiences with long-term supports and services for their family member with Intellectual or Developmental Disabilities (IDD). We analyzed data from the National Core Indicators family surveys that were completed in 2012 through 2014.

The purpose of this report was to look at self-reported family outcomes in relation to the age and health of the caregiver.

We found that the parents responding to this survey reported that they were generally satisfied with the supports and services their family member received.

The health of the caregiver and the level of support needs of the family member with IDD were important factors in the level of satisfaction with support outcomes. The age of the caregiver was less important, although there were some differences across age groups.

THE PURPOSE OF THIS REPORT WAS TO LOOK AT SELF-REPORTED FAMILY OUTCOMES IN RELATION TO THE AGE AND HEALTH OF THE CAREGIVER.

## Background



An estimated 1.2 million people with IDD are receiving LTSS and about half of those individuals live with family members<sup>1</sup>. It should be noted that an estimated 70% of individuals with IDD living with their families do not receive federally-funded Long-term Supports and Services (LTSS). An estimated 29% of the population provides some level of care for a family member with disabilities, chronic illness, or who is aging<sup>2</sup>. As both individuals with IDD and their caregiver's age, the need for a responsive support system that addresses the needs of both the individual with disability and that of the family is crucial to successful outcomes for individuals and their families.



The National Core Indicators (NCI) is a voluntary program used by public developmental disabilities agencies in 43 states to measure and track service performance and outcomes. The NCI family surveys are paper surveys sent by states to families of children or adults living in their family home. The

### THE NEED FOR A RESPONSIVE SUPPORT SYSTEM THAT ADDRESSES THE NEEDS OF BOTH THE INDIVIDUAL WITH DISABILITY AND THAT OF THE FAMILY IS CRUCIAL TO SUCCESSFUL OUTCOMES FOR INDIVIDUALS AND THEIR FAMILIES.

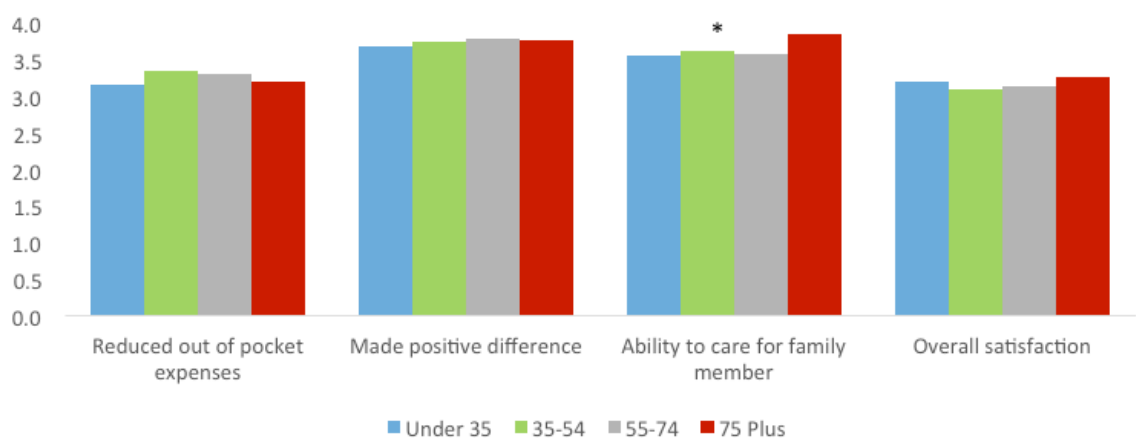
2012-2013 and 2013-2014 surveys includes 22 states with a total of 19,241 respondents across these states. About 60% of the respondents were caregivers for individuals with IDD aged 22 and older. Most of the respondents (89%) were parents (the rest were spouses, siblings, or other).

For this report, we examined how caregivers across age groups reported their satisfaction with family outcomes. Caregivers were asked to rate, on a 5-point scale (0-4), the extent to which the long-term services and supports their family member received reduced their out of pocket expenses related to their family member's care, increased their ability to care for their family member, improved the life of their family member, and with their overall satisfaction with services. In addition to looking at the age of the caregiver, we also looked at the health of the caregiver and the level of support needs (ADL, behavior support, medical care, and mode of communication) of the family member with disabilities as factors that may influence family outcomes.

# Findings

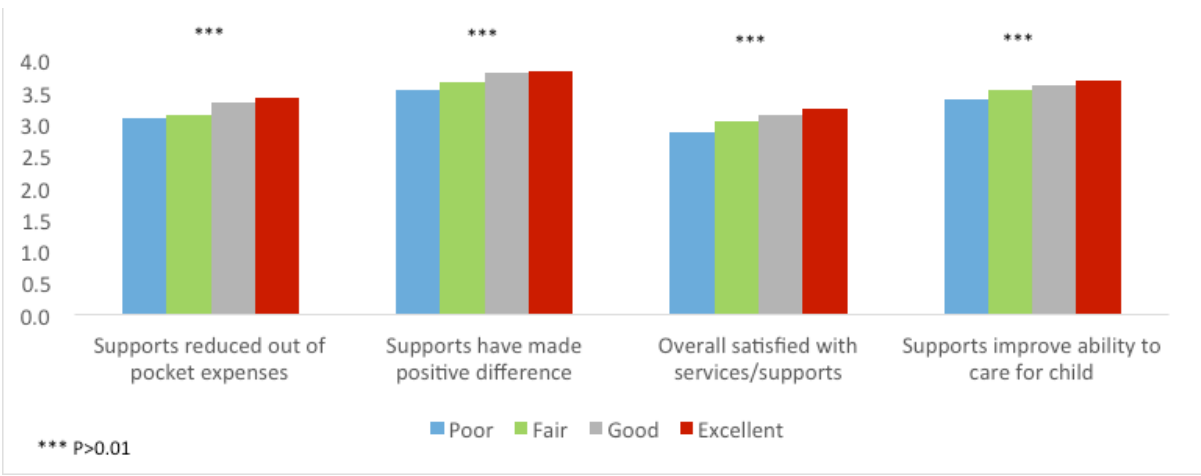
The mean scores for each of the outcomes for caregivers across all of the age groups was similar and, in general, the caregivers responding to this survey were satisfied with services. Caregivers 75 and older were the most satisfied with supports and services increasing their ability to care for their family member and were least satisfied with the extent to which supports and services reduced out of pocket expenses. Overall, younger caregivers (35 and younger) were somewhat less satisfied with the extent to which supports and services reduced their out of pocket expenses, made a positive difference in the life of a family member, or increased their ability to care for their family member. Younger caregivers were more likely to report that their family member had ASD and had higher supports needs. The only outcome in which there was a statistically significant difference across the age groups was the extent to which supports and services improved the caregiver’s ability to care for their family member.

## Caregiver Ratings of Family Outcomes by Age of Caregiver



The health of the caregiver played a much bigger role in explaining the differences in reported outcomes of family members than did age. Caregivers who reported overall poorer health were less likely to be satisfied with the extent to which supports and services reduced their out of pocket expenses, made a positive difference in the life of a family member, or increased their ability to care for their family member, regardless of the age of the caregiver.

## Caregiver Ratings of Family Outcomes by Health Status of Caregiver



## Summary



Overall, the majority of families who completed the survey indicated high levels of satisfaction with services. There are some differences in experiences with LTSS across the different age groups of parents responding to this survey. However, differences in satisfaction with family outcomes was more dependent on the caregivers self-reported health status regardless of age. As noted earlier, the majority of persons with IDD and their families do not receive LTSS services. Therefore, their experiences are not reflected in these data. Additionally, less than 30% of those receiving LTSS services responded to the survey. Further attention to the experiences of families who did not respond to these mailed surveys is needed. In order to provide LTSS that best meet the needs of individuals with IDD and their families, recognizing the changing health status of caregivers and the role of family supports in family outcomes of families with a family member with IDD is important.

IN ORDER TO PROVIDE LTSS THAT BEST MEET THE NEEDS OF INDIVIDUALS WITH IDD AND THEIR FAMILIES, RECOGNIZING THE CHANGING HEALTH STATUS OF CAREGIVERS AND THE ROLE OF FAMILY SUPPORTS IN FAMILY OUTCOMES OF FAMILIES WITH A FAMILY MEMBER WITH IDD IS IMPORTANT.

## References



<sup>1</sup>Anderson, L.L., Larson, S.A., Kardell, Y., Hallas-Muchow, L., Aiken, F., Hewitt, A., Agosta, J., Fay, M.L., & Sowers, M. (2015). *Supporting Individuals with Intellectual or Developmental Disabilities and their Families: Status and Trends through 2013*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

<sup>2</sup>Family Caregiver Alliance. (2012). Selected caregiver statistics. Retrieved from <https://www.caregiver.org/selected-caregiver-statistics> on 11/1/15.

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