



## Family Experiences with 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. We analyzed data from the National Core Indicators family surveys that were completed in 2012 and 2013. The purpose of this report was to look at differences across racial and ethnic groups.

We found that the parents responding to this survey reported that they were generally satisfied with the supports and services their family member received. There were some differences with experiences reported by Black, White and Latino parents. It should be noted that the response rate to this survey was less than 30% and that most people with IDD living with families do not receive federally-funded Long-term Supports and Services.

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## Background



Most people with IDD of all ages have always lived in the homes of family members, however federally-funded Long-Term Supports and Services (LTSS) for people with IDD living in the home of a family member has grown significantly in the past 35 years<sup>1</sup>. Reasons for these changes include the Medicaid Home and Community Based Waiver which started in 1981 as well as legislation such as the Individuals with Disability Education Improvement Act (IDEIA) and the Americans with Disabilities Act (ADA). These programs along with Medicaid programs that provide long-term support funding mechanisms have made it possible for people to receive supports in their family home. 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 LTSS.

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 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 sent by states to families of children or adults living in their family home. The 2012-2013 survey includes four states that provided data for both the Adult and the Child Family Surveys (Louisiana, North Carolina, Ohio, and South Carolina), six states that fielded only the Child Family Survey (Arizona, Connecticut, Oregon, Texas, Virginia, and Washington), and nine states that fielded only the Adult Family Survey (Florida, Georgia, Kentucky, Maryland, Michigan, Missouri, Oklahoma, Pennsylvania, and Utah). A total of 3,199 families responded to the Child Family Survey (CFS) and 3,606 responded to the Adult Family Survey (AFS). The response rate for these surveys was 24% for the CFS and 29% for the AFS. Most respondents reported speaking English. For this report, we examined how White, Black and Latino parents reported their experiences with the LTSS their family member received.

### We looked at the following areas:

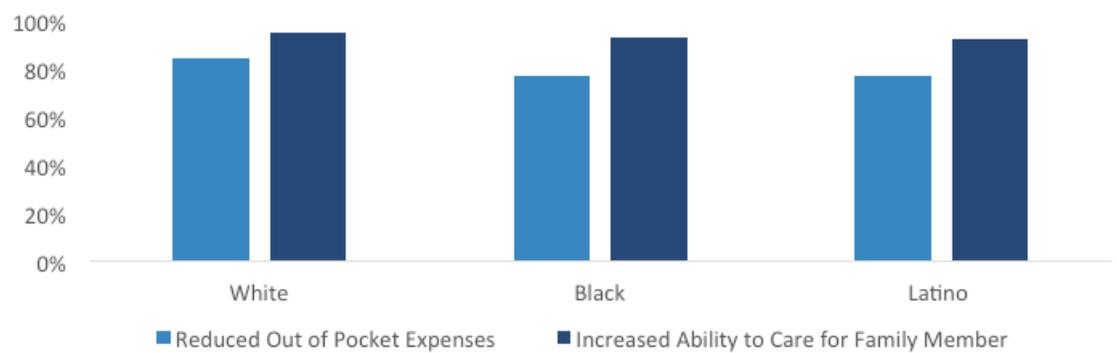
1. **Information** (getting adequate information about supports and services);
2. **Planning** (the extent to which families are involved in planning services);
3. **Service Delivery** (experiences with service delivery such as staff availability);
4. **Access to Health Care** (medical and dental care);
5. **Access to Community Supports** (respite, mental health supports, transportation);
6. **Choice** (the extent to which families can choose service providers); and,
7. **Control** (the extent to which families report that they are aware of and have control over resources).

We also compared overall satisfaction with services, the extent to which services were culturally appropriate, the extent to which services reduced out of pocket expenses, and the extent to which parents reported that services made it easier for the parents to care for their family member. The state of residence, families' income level, parents' education level, and support needs of the family members with disabilities were accounted for in the analysis.

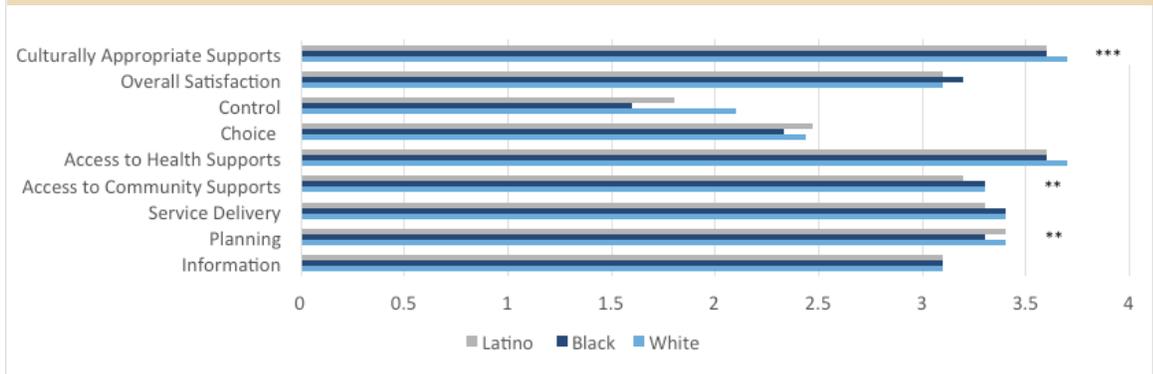
# Findings

- Most of the parents responding to the survey reported relatively positive experiences with the LTSS their family members received.
- Parents, regardless of background, reported relatively lower satisfaction with control or knowing what their service budget was and being able to direct how those resources were used.
- Latino parents were less likely to report that the services they received were respectful to their family's culture.
- Black parents were less likely to report that they received adequate information about supports and services.

## Percent of Parents Reporting Reduced Out of Pocket Expenses and Increased Ability to Care for Family



## Parents' Self-reports with Long-term Supports and Services, 2012-2013 NCI Family Survey#



## 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 White, Black and Latino parents responding to this survey. 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, all families should receive more information about the resources allocated and have the opportunity to direct those resources to the most appropriate services. State IDD agencies, case managers, and service providers need to ensure that all families receive adequate information about supports and services for their family members. Future research is needed to understand the experiences of families of individuals with IDD who are not in the LTSS system.

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## 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.

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