What is the Supporting Individuals and Family Information Systems Project?

The Supporting Individuals and Families Information Systems Project (SIFISP) collects information from states to understand the status in supporting families and individuals with Intellectual and Disabilities (IDD) living in homes of their own or with family members (including consumer direction).

Data is provided by the offices that provide IDD services in each state. Each year they are asked to provide information about where people who receive services live, the ages of people receiving Long-term Supports and Services (LTSS), and expenditures for LTSS.

This report only includes information about people who are receiving services. Not all states are able to report on all of the information.

What are the living arrangements of people with IDD who receive LTSS?

States report on the types of places people live. Congregate settings are where four or more people with IDD live together and receive long-term supports and services. This can mean small community group homes, nursing homes, or other kinds of group settings. People may also live in their own home or in their family home. Some people live in host homes or family foster care.

On June 30, 2012, more than half of the people who received LTSS lived with a family member (56%). Another 10% lived in a home they owned or leased with no more than two other people with IDD, 6% lived in a group setting shared by three or fewer people with IDD, and 5% lived in a host family or foster home shared by three or fewer people with IDD, and 23% lived in congregate settings.

How many HCBS waiver recipients live with a family member?

Since 2006, roughly half of all Home and Community-Based Service waiver recipients lived with a family member. About 55% of all service recipients lived with a family member.
Proportion of People with IDD Who Live in the Home of a Family Member

On June 30, 2012, an estimated 634,988 people with IDD (56%) were living in the home of a family member.

Arizona (86%), South Carolina (71%), California (71%), Delaware (70%), and New Jersey (70%); reported the greatest number of people living in their family homes. Hawaii, Louisiana, Massachusetts, Nevada, New York, and Ohio also reported more than 60% of the people known to state IDD agency lived in the home of a family member.

States reporting the smallest proportion of people living in the home of a family member were Nebraska (21%), Alaska (20%), Connecticut (16%), New Mexico (15%), and Virginia (13%).

Iowa and Illinois were not able to report the number people with IDD living in the home of a family member.

For an interactive version of this table, visit fisp.umn.edu/dataviz.