

Background:

**HOUSING ISSUES FOR ADULTS WITH INTELLECTUAL
DEVELOPMENTAL DISABILITIES IN HAWAII**

Prepared by FULLER LIVES, Inc.
ADVOCATING, EDUCATING, EMPOWERING

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HISTORY

A **Developmental Disability** is a diverse group of chronic conditions that are due to mental or physical impairments. Developmental Disabilities cause those living with them many difficulties in certain areas of life, especially in "language, mobility, learning, self-help, and independent living" that may be lifelong. Developmental disabilities may be physical, such as Cerebral Palsy, or Intellectual, such as Autism and Down Syndrome. Particularly, people with Intellectual Developmental Disabilities (IDD) can be expected to require a lifetime of support and assistance.

Society has long recognized that a proportion of the population will have disabilities that require special care over a lifetime. In 1919, Hawaii created what was later called Waimano Training School and Hospital, an institutional incarceration facility for people with IDD. As society became more knowledgeable, and sophisticated, the difficulties and detriments of running large institutions led to favoring community approach to the care of the developmentally and intellectually disabled.

HAWAII'S PROMISE

The goals of "community care" are laudable: people would be part of their community, and the relationships would improve their functioning. In 1990, Hawaii closed the Waimano home, adopting the community care model. This, however, necessitated the decentralization of care, so Hawaii set up a system that provided for day programs and necessary additional services. Hawaii passed Act 341, which established a bill of rights for individuals with DD/MR that included the right to receive services and live in residences in the least restrictive, individually appropriate manner located as close as possible to the person's home community within the State, and the right to live in a setting that is closely similar to those available to non-disabled persons of the same age.²⁵

Act 341 became codified in the Hawaii Revised Statutes as Section 333F ("H.R.S. § 333F") and laid the foundation for DOH's policy away from institutionalization and towards community-based services and supports.

THE PRESENT

Today, however, it is apparent that this promise is not being met. Families looking for housing for their adult child with IDD are told the waitlist for housing is typically ten years. Moreover, when finally assigned housing, it is most UNlikely that the adult child will be able to remain in his/her home community, as promised.

There are two critical forces in play:

1. A statewide shortage of housing for this population
2. Appropriate housing options are often not available in the home community, especially in East Honolulu, the Windward side, and the outer islands

LACK OF HOUSING

Given the prevalence of ID in adults as 4.94 per thousand, and a 2015 Hawaii population of 1,421,603, we would expect there to be 7,072 adults with Intellectual Disabilities in Hawaii. (Maulik (2011), Prevalence of Intellectual Disability. *Research in Developmental Disabilities*, 32,p. 419-436) The Hawaii Department of Health reports 3,153 recipients of Long Term Supports and Services that year. (2015 DOH RISP report)

For most of these clients, housing alternatives outside the family home are unavailable. These alternatives are domiciliary homes, which can house a maximum of 5 clients, and foster families, which can only care for two clients. In 2015, domiciliary homes housed 341 adults, foster homes housed 486, nursing homes or psychiatric facilities housed 73, and 78 lived in a home they owned. The rest, a total of 2,241, resided with their families. (2015 RISP) For most of these families, having their adult reside with them works well—for the time being. As parents age, they become less able to provide the necessary care for their children, who themselves need more care as they age. Here's the issue: what is available for these adults who cannot care for themselves but cannot continue to rely on aging parents?

Clearly, with ten year waitlists, the system is already filled. Anecdotes abound among worried parents concerned for their children's future. This author, a parent to a child with IDD, experienced the shortage firsthand when her son's friend needed a home. The social worker searched diligently, but could not find a home for this young adult. She expressed frustration to me, noting that the client would just have to find a place to live on her own on the limited \$700 she received from SSI. Knowing that this would be extremely dangerous, given the vulnerability that comes along with Intellectual Disabilities, I agreed to provide a home temporarily, just until the social worker found a permanent placement. Two years later, the young lady moved out, but only to another "temporary home", as her name had not yet come up on the waitlist for housing. We need more beds available to meet the need.

The Center on Disability studies at the University of Hawaii reports that case managers have reported that the state has a shortage of 100 beds. (*Analysis of Impediments to Fundamental Housing Choice with a Focus on People with Disabilities*) Nov 2016, p. 48). If they had spoken to the caregivers of the adults with IDD to develop the numbers, the reported shortage would have been much higher. Masking the pronounced shortage is the strong desire of families to ensure the well-being of their children. Knowing that there is no alternative to living with their families, aging parents continue to serve as caregivers, often to the detriment of their own health. The Department of health reports that 27 % of caregivers are 60 or older (2015 RISP) so 605 adults with Intellectual Disabilities depend upon an elderly caregiver. Many of these families would prefer to have their adult child live in a domiciliary home or a foster care home to get used to being more independent before the inevitable day comes when they are forced to leave the home due to the death or disability of the family/parent caregiver.

LOCATION OF HOUSING

Finally, a major problem with the system, and adding to parents' reluctance to seek alternative housing for their adult child, is the skewed geographical distribution of the housing resources available for this group. If you live in East Honolulu, between Makiki and Hawaii Kai, you are almost guaranteed that your child will NOT be able to continue to live in the community he/she calls home, for there is only one only domiciliary home and fewer than a dozen foster homes in that area—and they are all filled. If your child was lucky enough to find an open spot, it would be many (10-30+) miles away in a community he/she did not know. All those community connections developed over the years in the home community, would be lost—the school friends, the church friends, the familiarity with the stores, library, playgrounds, favorite snack spots and employment would be lost. For anyone moving into a new community in midlife, making new connections is difficult. For someone with IDD, it can be overwhelming.

DELIVERING THE PROMISE

FULLER LIVES is a brand-new 501c-3 organization that has been created by parents to resolve these problems. We are devoted to increasing housing options for our children that will allow them to remain in their home communities throughout their lifetime as envisioned in community care. We are determined to collaborate with government, community organizations, and the public to find solutions. We look forward to the input, information, and assistance you might provide.

FULLER LIVES

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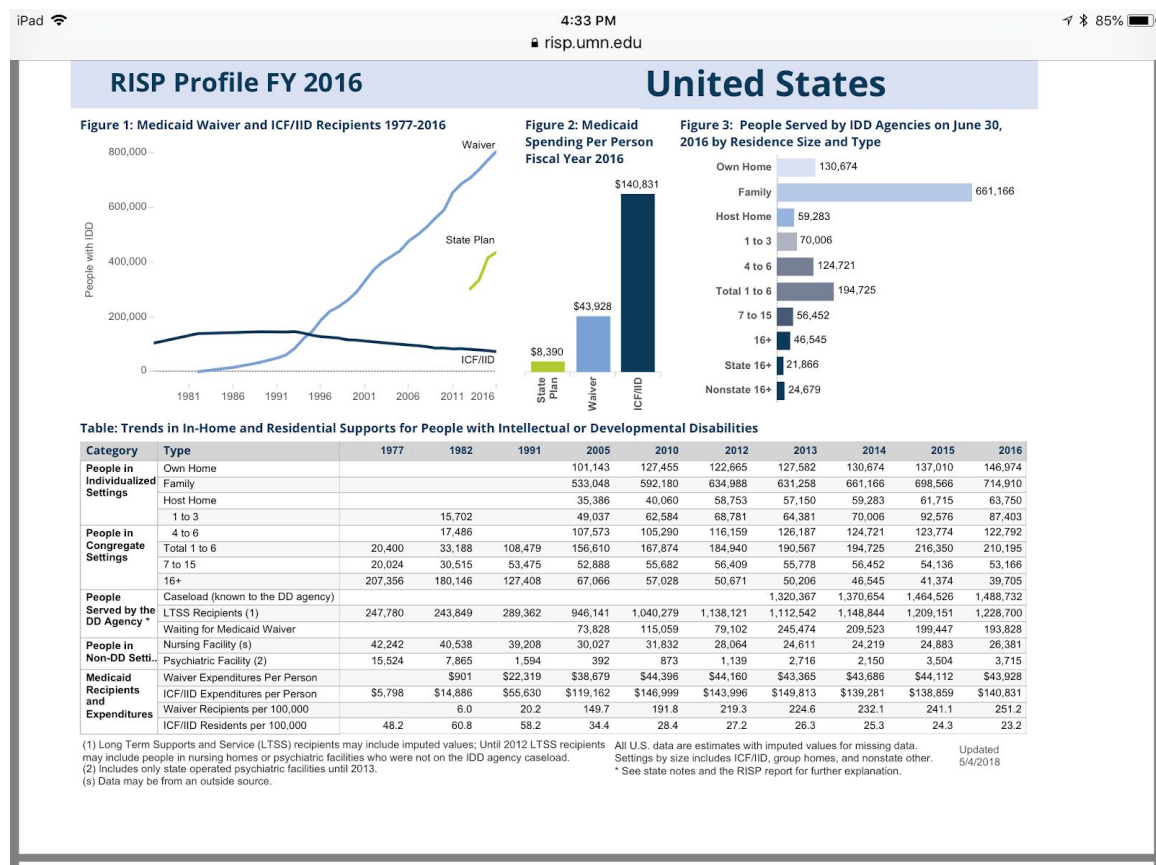
ADDENDUM: UPDATE ON HOUSING NEEDS USING 2016 HOUSING DATA

Attached are the 2016 RISP reports for the United States and Hawaii

The data reflects that nationally, 42% of recipients of LTSS with IDD are housed outside the family home. If Hawaii was to House a similar percentage of IDD recipients of LTSS outside the family home, we would need to have 321 more beds available, spread across domiciliary homes, foster care, and rentals recipients of services can afford.

We realize that cultural differences may lead to a higher percentage of Hawaii LTSS recipients with IDD desiring to stay in their own home. However, these cultural differences would not support the large disparity shown here. Hawaii needs to increase housing for its population with IDD. Fuller Lives is committed to improving the situation.

RISP data is found at : RISP@umn.edu



RISP Profile FY 2016

Hawaii

Figure 1: Medicaid Waiver and ICF/IID Recipients 1977-2016

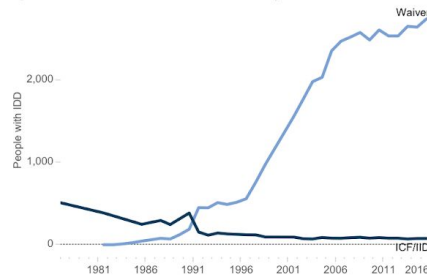


Figure 2: Medicaid Spending Per Person FY 2016

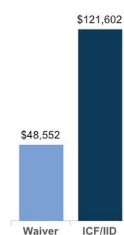


Figure 3: People Served by the IDD Agency on June 30, 2016 by Residence Size and Type

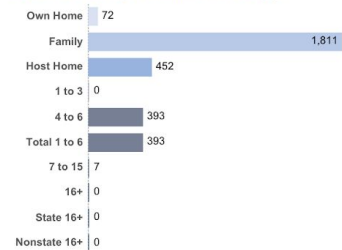


Table: Trends in In-Home and Residential Supports for People with Intellectual or Developmental Disabilities

Category	Type	1977	1982	1991	2005	2010	2012	2013	2014	2015	2016
People in Individualized Settings	Own Home				150	48	123	123	180	78	72
	Family				2,108	1,584	2,202	2,202	2,078	2,241	1,811
	Host Home				740	554	669	669	448	486	452
	1 to 3				3	3	0	0	0	0	0
	4 to 6				164	163	227	227	239	341	393
People in Congregate Settings	Total 1 to 6	366	445	948	167	166	227	227	239	341	393
	7 to 15	18	12	7	8	8	7	7	0	7	7
	16+	543	400	146	0	0	0	0	0	0	0
People Served by the DD Agency *	Caseload (known to the DD agency)							3,281	2,756	3,349	3,322
	LTSS Recipients (1)	927	857	1,101	3,173	2,360	3,281	3,228	3,113	3,153	2,735
	Waiting for Medicaid Waiver				0	0	0	0	0	0	0
People in Non-DD Settings *	Nursing Facility (s)			138	103	87	53	61	61	68	68
	Psychiatric Facility (2)			0	0	0	0	DNF	DNF	5	6
Medicaid Recipients and Expenditures	Waiver Expenditures Per Person			\$16,148	\$35,279	\$40,088	\$40,452	\$40,452	\$39,210	\$39,744	\$48,552
	ICF/IID Expenditures per Person			\$19,406	\$97,790	\$114,104	\$97,653	\$105,467	\$125,732	\$121,602	\$121,602
	Waiver Recipients per 100,000			16.7	160.0	183.4	182.7	181.2	187.5	185.2	192.7
	ICF/IID Residents per 100,000			34.0	6.9	5.8	5.7	5.6	4.9	5.3	5.3

(1) Long Term Supports and Service (LTSS) recipients may include imputed values; Until 2012 LTSS recipients may include people in nursing homes or psychiatric facilities who were not on the IDD agency caseload. Settings by size includes ICF/IID, group homes, and nonstate other.
 (2) Includes state operated facilities until 2013. DNF = Did Not Furnished.
 (s) Data may be from an outside source. PD = Partial Data.
 * See state notes and the RISP report for further explanation.

Updated
2/14/2018

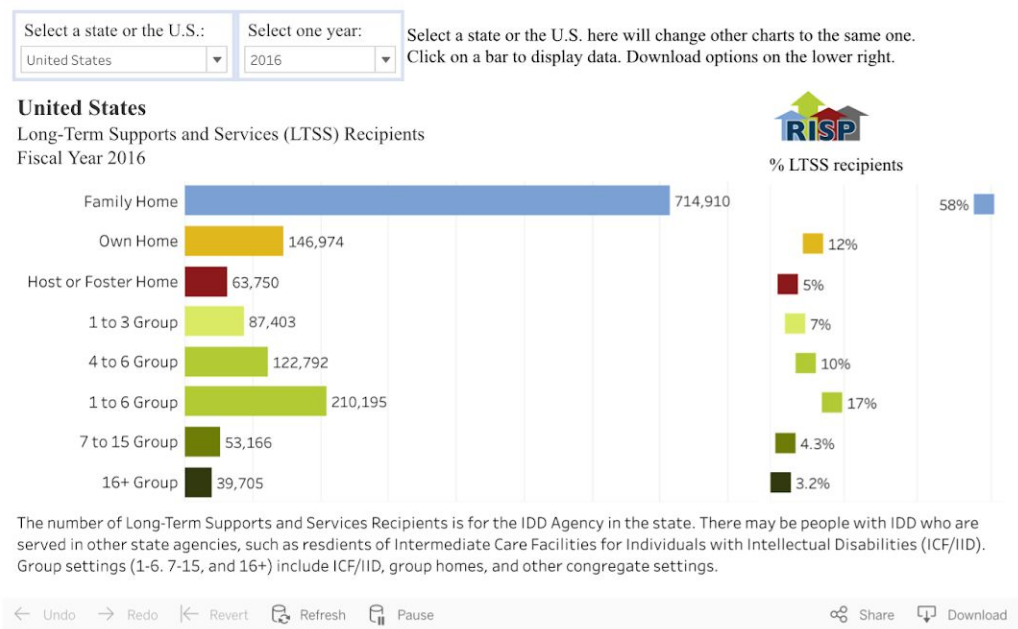
Chart Gallery



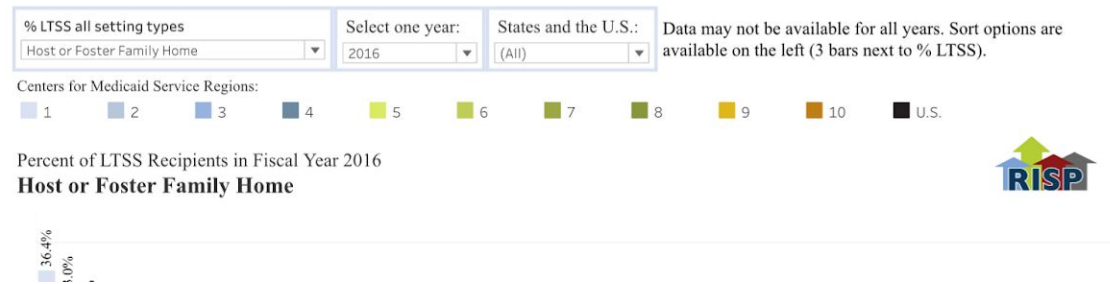
Charts on living arrangements, people served, and Medicaid are below, also see charts on [Medicaid Waivers](#) and [Medicaid ICF/IID](#)

Living Arrangements

Long-Term Supports and Services (LTSS) Recipients by Setting Type and Year



Compare States: Percent of LTSS Recipients by Setting Type



Hawaii

State Notes

None.

Data for years not shown can be viewed in the [Chart Gallery](#) of the [RISP.umn.edu website](#). Survey questions and operational definitions can be found in the [Publications](#) section. See the FY 2016 report text for details about methodological changes that may have changed values reported from one year to the next (particularly for the waiting list questions).

Larson, S.A., Eschenbacher, H.J., Anderson, L.L., Taylor, B., Pettingell, S., Hewitt, A., Sowers, M., & Bourne, M.L. (2018). *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities: Status and trends through 2016*. Minneapolis: University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration.

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Reading the State Profiles

Unless otherwise noted, the profile shows values furnished by the state IDD agency. Blank spaces or breaks in a trend line indicate years a data element was not collected or a state provided incomplete or no data. Large year-to-year changes often reflect changes in state data sources or methodology, the addition or termination of a funding authority, or inclusion of a narrower or broader set of recipients. The State Notes describe variations from the survey definitions, alternative data sources used, reasons for large year-to-year changes, and other factors affecting data interpretation.

Figure 1 shows the number people living in Medicaid Intermediate Care Facilities for People with Intellectual Disabilities (ICF/IID) between 1977 and 2016 and the number of Medicaid Waiver recipients with IDD between 1982 and 2016.

Figure 2 shows the average annual per person Medicaid ICF/IID and Waiver expenditures for the year ending June 30, 2016.

Figure 3 shows the number of LTSS recipients with IDD living in various residential settings on June 30, 2016. Setting types include the home of a family member, a person's own home, a host/family foster home, and IDD group settings by the number of LTSS recipients per home (1 to 3, 4 to 6, 1 to 6, 7 to 15, or 16 or more people). Data may be shown for the 1 to 6 people category even if a state did not furnish complete data for settings of 1 to 3 people and 4 to 6 people.

The Table shows the number of LTSS recipients with IDD living in settings of various types and sizes, and the number of people on the IDD agency caseload, or receiving or waiting for LTSS by year. It also shows average annual per person Medicaid Waiver and ICF/IID expenditures, and Medicaid Waiver and ICF/IID recipients per 100,000 of the state's population.